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Canter, Richard John

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CLINICAL DECISION MAKING IN A SURGICAL OUTPATIENTS:

RELATING THE SCIENCE OF DISCOVERY WITH THE SCIENCE OF IMPLEMENTATION

Submitted by

Richard John Canter

for the degree of

PhD
of the University of Bath.

1998

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To my wife Julia,
my children Rachael and Laurie
and my parents

Summary

This thesis is an account of how I researched my clinical practice. In **catalyst for research**, I begin by noticing the difficulty of applying clinical knowledge with due regard to the setting of the clinical problem and observe that on occasions my decisions are influenced by medical guidelines and on other occasions by the demands of context. I suggest that some sort of framework is needed to cope with these competing demands. **Acquiring the scientific basis of medicine** examines my educational upbringing at school and university and concludes that I have been taught to recognise as valid in the clinical context only certain kinds of knowledge (quantitative). With this in mind, the sections **medical knowledge** and **restructuring the meaning of scientific knowledge** reframes my practice and hospital environment through cultural and historical perspectives, which loosens some of my firmly held assumptions about relevant data to describe medical processes. The **methodology** section explores epistemology and methodology with reference to one of five paradigmatic positions and concludes that a methodology researching practice must generate and integrate data from different paradigms. **Reflective clinical practice** traces my development as a qualitative researcher from positivism to constructivism as I sought to explore non-clinical processes in the clinic. This results in the development of a three layer conceptual model of doctor, reflective practitioner and researcher. I argue that this extended epistemology has enabled me to pay greater attention to non-clinical processes that define the clinical landscape and to recognise the unique position of every clinical problem. **Conclusions** seeks to evaluate what I have learnt from the research and suggests that the theory underlying this approach may deserve wider attention.

CLINICAL DECISION MAKING IN A SURGICAL OUTPATIENTS: RELATING THE SCIENCE OF DISCOVERY WITH THE SCIENCE OF IMPLEMENTATION

SCENE SETTING

About the writer.

I am aged 45. I qualified in medicine in 1976 and, after a period of training that took me from London to Bristol to Liverpool then Toronto, was appointed a consultant surgeon at the Royal United Hospital, Bath, England in 1987 and an Honorary Senior Lecturer in the School of Postgraduate Medicine in 1991. The department consists of four consultants and nine trainees and is part of the South West of England post graduate training programme in Ear, Nose and Throat Surgery. Teaching these trainees is a major commitment of the department. As a consultant I see approximately 3,500 patients in the clinic and undertake surgery on between 400 and 500 per year.

I spent seven years doing research into the non-clinical processes of decision making in my practice and submitted this as a thesis a year ago. I have had to resubmit the thesis and in this prelude I would like to explain how I tried to make this setback part of the inquiry process. In doing it this way, I hope to demonstrate some of the skills of inquiry called for by the examiners. For example, it has given me the opportunity to reframe 'error' in such a way that it becomes an inquiry. The resubmission made me aware of some key issues that underpin the thesis as a whole. One issue in particular needs highlighting. I have become aware of the fragile research process needed in suspending belief (and criticality) in order to shift paradigms but at the same time retaining sufficient criticality to monitor that shift in a way that is perceived as credible. There have been substantial changes throughout the text but one section in particular has been completely rewritten; the methodology section. Whilst re-writing this section, it seemed to me that it was necessary not only to enter at a level where I needed to reconstruct what didn't happen but I also needed to reconstruct what did happen but in a way that was authentic and at the same time credible. In summary, part of the argument that I put forward when resubmitting this thesis is that my experience in the qualitative research arena in the last few years has equipped me with

sufficient expertise to handle the difficulties associated with resubmission. I see this approach as providing a level of methodological coherence with the rest of the thesis. Whilst advancing this stance, I am aware of the counter-argument that this approach may be regarded as no more than *post hoc* justification. For these reasons I have written an introduction that is at greater length that might at first sight seem necessary in order to highlight in more detail some of these issues.

What has been rewritten?

The methodology section has been almost completely rewritten. This shouldn't imply that the methodology itself has been retrospectively reconstructed but the understandings associated with the methodology have been. The section on power has also been developed. I have also tried to portray the 'other voices', those of the patients who I have interviewed and with whom I have co-researched, in more detail. These changes alone have encouraged me to rethink other sections and I have made many alterations but without altering the original structure too much. This process has highlighted the problem of clarity versus complexity. In respect of clarity, I am especially aware that the nature of the academic process is such that this has to be a last attempt so that I need to be sufficiently clear for the purposes of examination. This makes it difficult to resist the temptation to pursue it past the point of tidiness. In respect to complexity, on the other hand I see the need to avoid becoming so clear that the complexity of what I am trying to unravel has apparently escaped. This dilemma is clearly a power issue within the examination process but similarities with the doctor patient relationship, where I suspect patients struggle to achieve a balance between complexity and clarity, are also not lost on me.

Why was a resubmission necessary?

As a qualitative researcher, this was the first question I asked myself. It lead to many other questions but one in particular; what kind of PhD had I envisaged? From the beginning, I

had envisaged a kind of hybrid PhD, a hybrid between a qualitative, organisational behaviourist research approach and a traditional medical research approach to outpatient processes. There already existed a model for such an approach. Medical researchers frequently have recourse to statistics and work with biostatisticians to analyse data, so that such a model of collaboration along those lines seemed superficially plausible. I perceived that my traditional training as a doctor would enable me to handle the *clinical* processes of decision making and this exploration into the qualitative research field would enable me to handle the *non-clinical* processes of decision making. This conceptual separation of quantitative and qualitative features, which I retained until very late into the thesis, was a kind of dualism where the clinical issues ('the one's that really mattered') were 'managed' by the non clinical issues. What I was not prepared for was the major rethink has taken place in what I regard as relevant epistemology. Both clinical and non-clinical processes now seem to be of equal importance. In retrospect, seeing the PhD as a collaborative approach between qualitative and quantitative traditions was a major assumption on my part, the first of many it seems. Recognising it, prompts general considerations as to why such assumptions arise in the first place and secondly, why, in my particular case, the level of assumption was so high.

Assumptions help to make data manageable so that removal of all assumptions tends to leave a messy problem to analyse. Underpinning assumption, therefore, is the question of choice and the exploration of these assumptions involves the exploration of choice. Morgan (Morgan, 1983. p19-44) has identified five approaches to making sense of the diversity found after exploration and understanding. The first approach he called s*upremacy.* Different paradigms carry with them a different set of generally agreed assumptions so that "one response to the existence of different research assumptions is to call for some evaluation or test that will determine their merits." He concluded that "this attempt to evaluate different research assumptions in a foundational sense encounters the same kind of relativism as that with which it is attempting to deal." Such a hierarchical approach leads to the insoluble confrontation of the relative merits of quantitative versus qualitative research approaches. The second he called s*ynthesis.* This "is concerned with

finding an optimal way of conducting research.....an attempt is made to find ways of combining the strengths (among different research assumptions) and minimizing their weaknesses". The variety and complexity of different paradigms in social research has in part resulted from this kind of activity. The third approach he called *contingency.* This is an empirical approach that adopts the view that "assumptions and knowledge should be judged according to their usefulness"(ibid). As I hope to demonstrate, this is very much the kind of approach that I had embedded within my clinical practice. Fourthly, he proposed a d*ialectic* approach to assumptions. This approach accepts the "diversity of assumptions and knowledge claims as an inevitable feature of research and attempts to use the differences among competing perspectives as a means of constructing new modes of understanding."(ibid) Such an approach takes advantage of different perspectives with different sets of assumptions in the hope that new insights would emerge. Finally, the idea that a*nything goes.* This approach adopts a complete relativism, favouring the idea that every research strategy may have something to offer, and whether or not we attempt to systematise insights is of little real concern. This approach "stems from Feyerabend's advocacy of a theoretical and methodological anarchism in science on the basis that there is no idea, however ancient or absurd, that is not capable of improving our knowledge." (ibid) A researcher who has come to the conclusion that the search for grand narratives, for paradigmatic uniformity is over, might take such a view. Morgan himself concluded that "there are no external, fixed foundational bases for deciding what is best and that the argument that "anything goes" is quite strong." (ibid)

I started this research with the assumption that I was capable of acquiring the necessary research skills as an extension of the research skills I already possessed. This attitude was mistaken. The research skills necessary for conducting my PhD were not simply an extension to my current research skills but were developed in association with a fundamental shift on my part in ontological viewpoint. As a result, I was slow to uncover unaware assumptions that become important when shifting from a positivist or possibly a post-positivist ontology, where context has been 'stripped', to a constructivist ontology

where the significance of context is obviously central. Argyris et al have drawn attention to this problem when talking about research students.

"Success depends on setting levels appropriately...ordinarily they look to past performance. Yet this is precisely where participants run into difficulty. Their perception of their performance is likely to be quite different from their actual performance. They have been unaware of their theories, the outcomes they produce, and the actions they inform. They are thus apt to believe that they already have the skills or that they will be relatively easy to learn." (Argyris, Putnam, et al, 1985. p290-291)

Last of all I found myself asking whether there was something about the nature of the organisation within which I work, in political, cultural, power or whatever terms, that permit such a high level of assumption to flourish? As a doctor I hold a rather traditional position within society and could be succinctly defined as a white, middle class male engaged in a white middle class profession. This whole position brings with it levels of assumptions, both personal and organisational, that may not be immediately apparent to those who occupy such positions. Others have suggested more clearly what these are:

"one of the things that white, middle class men are taught is to believe that we are right....led to believe that the world will fall apart unless we hold ourselves together..... we have the right to control...defined authority in our own individual terms...ignoring a wider set of values....education encourages us to recreate the world in our own image...see life as the exercise of power, not as learning how to exercise power..... we have not learnt that we do not have to be right." (Vince, 1996 p140)

So in posing the question 'Why has this happened?' I find myself immediately confronting my expertise as a medical researcher, my high latent level of assumption and my status within society, particularly as an arbiter of what is 'right'. Given this position, what was my response to the setback of having to resubmit my thesis?

What were my initial responses to the setback of having to resubmit my thesis?

These responses included a certain level of embarrassment, both within my own department at work and personal. The personal embarrassment arose because this was my first real attempt to portray personal feelings and attitudes in the research process and call it 'research'. Whilst I instinctively recognised that this response in itself was going to be unproductive, I decided to accept the embarrassment until it became manageable and in time a source of motivation. This approach needed support so what support structure was I drawing upon during this process? My supervisors were immensely helpful during this time and encouraged me to investigate and re-evaluate the situation, as a research exercise. As a substantial part of my research had drawn on various forms of action science, I naturally turned to this approach.

"once we act (first order), we draw on backup strategies (second order) to manage the new situation that our initial actions created....second order strategies providing the opportunity to reflect on first order strategies and the situations they yield...protective strategies flow from a protective framing of errors." (Argyris, Putnam, et al., 1985 p292-295)

Argyris et al identified four main protective strategies; withdrawing, keeping reactions private, making face saving moves and asserting reactions unilaterally. (ibid)

1. Withdrawing and hold others responsible for withdrawing;

".....by withdrawing one avoids errors (or further errors)..but because this strategy renders experimentation and practice impossible, it is in itself a kind of error....it prevents individuals from discovering success that can be experienced in detecting errors and makes it easier to distort what one can and cannot do...this strategy cannot create a sense of

success..it increasingly generates a feeling of guilt....to defend against these feelings, actors soon begin to blame others for their withdrawal."

2. Keeping reactions private;

"...reactions that are kept private, consist of negative feelings and defensive attributions that serve to legitimate one's actions and take on an assumed to be true nature that lays the basis for further reasoning and action...e.g. appeal to one's sense of non competitiveness."

3. Making face saving moves;

"One such move is to criticise themselves while simultaneously criticising someone else...couch criticisms in a shroud of ambiguity....carry with them multiple messages..they are informed by rules of polite discourse, because such rules are shared, and because we know they are shared and that everyone else knows it too...this multiple message serves to put the recipient in a bind....on the one hand he may wish to be a good sport; while on the other hand he may be perplexed by the critique or even see it as inaccurate or unfair, but feel he will violate the rules by doing so."

4. Asserting reactions unilaterally;

"....making views public but doing so in a way that minimizes one's own vulnerability....at a high level of inference...making attributions which do not include data e.g. "you let it evolve", "you guided this".
(Argyris, Putnam, et al., 1985 p292-295)

I found myself carefully considering each one of these options. In doing so, I began to recognise that these protective 'framing of error' strategies were ones that I seemed to have already encountered in myself and among colleagues in medical practice when treatments and surgery do not proceed according to plan. The response of 'withdrawing'

is equivalent to referring the problem to another colleague; 'keeping reactions private' often forms part of defensive medical report of a problem; 'making face saving moves' seeks to extend the blame to other personnel or equipment, especially lack of it. Finally, 'asserting reactions unilaterally' is seen when doctors share stories of various medical mishaps with one another but present the story in a way that suggests that the outcome was beyond their control, for example an unexpected death from pulmonary embolus.

Such responses have probably developed in clinical practice because they are helpful or protective but in the situation I found myself as a researcher, they seemed inconsistent with a reflexive approach to inquiry. Furthermore part of my work had involved in depth interviews with patient who had experienced major setbacks (discovering that they had a life threatening incurable disease) and yet who sometimes seemed able to manage such setbacks sufficiently well to turn these into opportunities to learn. One way to encourage a shift in attitude from an irreconcilable position is to consider error as the raw data of learning.

"Errors are the raw material for any learning process. Curiously, this is a proposition that participants understand conceptually and advise others to follow but virtually all of them discard in action...there is no variance ...in how individuals frame mistakes; they simply regard them as wrong to make...Errors are considered taboo, and the possibility of making one stops them in their tracks....an alternative frame regards mistakes as puzzles to be engaged and solved, thereby making them opportunities for learning...It is not the mistakes...but the fact that people act as if these errors are not being made. A heuristic that is highly desirable for learning is to acknowledge what it is you are doing rather than cover it up."
(Argyris, Putnam, et al., 1985 p288)

Schon refers to the same position as 'stuckiness'.

"When he finds himself stuck in a problematic situation...he may construct a new way of setting the problem-a new frame, in what I shall call a 'frame experiment', he tries to impose on the situation."
(Schon, 1983 p63)

This process of 'error reframing' suggested abandoning the process of reconstructing my research into an acceptable format by covering error and instead approaching the resubmission task by considering what might be learnt from what happened. It was my father though who put it more pithily; "Success", he said, "was fine, but failure was far more interesting!" A useful question to ask in this position was; Why did it happen? One principal assertion by the examiners was that the level of critique in the thesis was at an insufficient level.

"The treatment of the specific concepts do not reach the criticality that is reasonable to expect at this level of scholarship."
(Examiners report-May 1997)

Assuming for a moment that I am capable of attaining an appropriate level of critique, I am led to ask; Why did my level of critique fall?

Why did my level of critique as a researcher fall?

First of all a number of obvious possibilities spring to mind; laziness, inability, lack of time within a busy job and inadequate supervision are some of them. However, even if I accepted such reasons, which I don't, as a researcher I would want to look beyond such a discouraging analysis. If my critique did fall, was it's previous level, suitable perhaps for a positivist ontology, hindering in any way the development of some other process? Certainly in my positivist world I had reached a point where every paper I read, every piece of research I encountered seemed to fail one criteria or another of validity. When I became interested in qualitative research, positivist perspectives on validity seemed to

challenge every assertion in the qualitative arena. Qualitative tests of validity such as quality, goodness, or trustworthiness made little sense to my quantitative validity procedures founded upon experimental reliability. Internal validity criteria such as credibility, supported by notions of triangulation and member checks, were difficult to comprehend by someone educated to understand controlled trials and p values. In the early stages, understanding the meaning of these terms proved to be a serious sticking point in trying to understand a qualitative ontology such as constructivism.

"It is necessary to examine and reframe the way we typically evaluate research.....there is a tendency for the criteria traditionally used to evaluate positivist research to be applied in the judgement of all knowledge claims.....the existence of such a foundational view hinders the development of research strategies seeking to produce different kinds of knowledge and hence hinders recognition and exploration of the full range of choice open to the researcher."
(Morgan, 1983 p392)

The only course of action I could adopt when I was undertaking this PhD research that allowed progress to be made, was to suspend belief in these positivist principles such as what constituted 'real' data or validity criteria and see where this led. There was a need to suspend for a moment beliefs in order to shift paradigms and this may be related to temporarily suspending criticality. A consequence of this had to be a lowering of critical standards, in particular a willingness to accept data uncritically, to make unsubstantiated interpretations readily and to constantly overlook assumptions as part of the process of shifting ontology. By lowering the level of critique, it allowed me to start accepting certain phenomena as 'data' and start to make new and qualitatively different inferences.

It must be remembered that all my previous research before I had embarked on this PhD process had involved identifying context (or bias) and then, in research terms, ignoring it. This resulted in a natural tendency of mine to regard bias as unimportant, unscientific, not subject to critique. Certainly, when I reviewed the initial thesis submission, I noticed how

disconnected my inference was from my data and the high level of conjecture present. In contrast, as I struggled to make the work of "sufficient scholarship", I also became aware of losing my ability to make interesting conjecture because of the academic need to substantiate conjecture with data. I found myself missing this lightness of touch.

"Books need not be subjected to totalizing judgements but would rather find criticism of scintillating leaps of the imagination so that they would not be sovereign dressed in red but would catch the sea-foam in the breeze and scatter it."
(Kritzman et al, 1977-84. p323-330)

As I began to unpick my assumptions when resubmitting, everything began to lose shape; data, theory, methodology, values, power were all dependent upon one another. I particularly noticed this in two ways. Firstly, I found myself eventually questioning the validity of the five main paradigmatic positions of positivism, post-positivism, critical theory, constructivism and participatory research (Guba, Lincoln, 1994 p105-117; Heron, Reason, 1997 p274-294) as nothing more than a peculiarly western way of looking at theory generation. Who was to judge whether this multi-paradigmatic perspective was any better than the single paradigmatic perspective I had striven to abandon. Secondly, as I sought to add validity to assertion by referring to data, 'everything' appeared to be relevant. Almost any example of text could be used to shore up any argument. Every line of interview transcription was loaded with gender, power and medical discourse.

As a partial, though unsubstantiated defence of the original submission, I also have a sense that the level of critique rose in the latter stages of the research process but the earlier uncritical approach made as part of the process of change, carried over into the text of original submission. This early research approach was more seductive than might at first appear because it was, in a sense, a development of a pattern of practice that forms part of the actual practice of medicine. Clinical practice can in one sense be viewed as a watered down version of ethnographic research.

"All ethnographers must impose meanings on their settings.....specifically they make inferences about the actors, guided by what ever theoretical perspective has helped them to frame their data. They do not publicly test their inferences (or the theories on which they are based) with the actors..... They end up imposing meanings on participants that may not be accurate, and thereby reducing the probability of learning on the part of both reader and practitioner.....chains of reasoning may go untested....."
(Argyris, Putnam, et al. 1985 p158-189)

This style of ethnographic research would seem to typify what actually happens in a clinic (Carter, 1997) and might appear to some to have the hallmark of good, patient orientated medical practice. This association with what has been perceived as good clinical practice may have reinforced the impression I had that what I was doing was 'real' qualitative research.

Was a lowering of critique a necessary stage?

For a researcher in my position it is possible to argue that lowering of critique may have been necessary to make the transition from quantitative to qualitative research methods. Equally necessary was the jolt back into an appropriate level of critique, exemplified by the rewrite. I can only propose that to abandon the process half way through, and not complete the rewrite, would have prevented me from sufficiently developing the process. The research cycle would have been incomplete. It was this instinctive feeling of being on the threshold of making this transition back to a higher level of critique (and understanding) that made me so determined to resubmit.

The demands of free and open inquiry-what to include and what to cover up.

The inquiry approach to resubmission outlined above enabled me to regard my initial 'mistake' as raw data that led to 'error re-framing' which in turn started to uncover some critical basic assumptions about my research. This still leaves unanswered the question

about what to include and what not to include in the interests of space in the rewrite and finally what, if anything, to cover up.

"Consider the demands of free and open inquiry. Participants must be able to retrieve largely tacit inferential processes; they must be able to deal openly with challenges and conflicting views; they must reveal information that might expose their own or other's vulnerabilities; they must be able to recognise and acknowledge when they are wrong; they must feel free to choose among competing views.....these requirements will foster learning, but they will also put participants at risk of disagreements, conflict, embarrassment, and failure, evoking defences to minimise such risks. The dilemma is that these defences come in forms that themselves threaten the process of inquiry....might conceal upsetting information, minimize or cover up conflict, go along with views they actually oppose, hesitate to submit their own views to criticism." p238
(Argyris, Putnam, et al. 1985 p238)

In order to appreciate what I might include and what I might wish to cover up or be unable to reveal, it is useful to put forward the basic methodological model which I see myself constantly using. I have tried to regard myself as working at three levels.

1. In my position as a doctor I operate at one level as a positivist (positivist theory generating data production).
2. At the same time I have tried to work as a reflective practitioner/ action inquirer (constructivist theory underlying nature of data and data production)
3. And finally as a researcher I try to develop an awareness of the ontological position I am adopting. This may be described as theory behind theory in that it represents an awareness of the assumptions circumscribing a particular paradigmatic position.

These levels are unravelled by constantly asking myself the question, "What is the theory behind the theory behind the data?" This simple formulation, and the inconsistencies within

it (for example can one be a constructivist and a positivist at the same time?) will be developed in more detail in the methodology section.

In this submission I have included very little reference to my practice as a positivist medical practitioner, utilising physiology, biochemistry, pharmacology etc. I see this aspect of my work as peripheral to the body of the thesis as a whole. In respect of my positions as a 'reflective practitioner/ action inquirer' and 'researcher' I have tried to adopt an approach that is as open as I can manage but there will always be some aspect of this process that I would regard as too personal to discuss. As a researcher, I have always felt mostly comfortable to be critiqued, admit error, re-evaluate any situation and in this role the level of conscious filtering feels much lower, but as a researcher I notice how hard it is to prove this.

The politics of it all

In addressing this issue I need to make one thing clear. The process involved in undertaking the rewrite has been enormously useful in clarifying many understandings I had only partly grasped. It has been a most useful and satisfying stage in my research. However, no discussion of the nature of a rewrite is complete without at least a reference to the political and disciplinary power issues in relation to the position of academic gate-keeping.

"Tension between recognition and failure, persistence and compromise demonstrates how disciplinary gatekeeping maintains academic structures so that they continually reproduce themselves as the same, and marginalise or reject any challenge."
(Banister, Burman, et al. 1994 p133)

In struggling to stand outside the disciplinary constraint of medical discursive practice and question it, have I fallen prey to the disciplinary constraints of academic discursive practice? This is not a good moment to marshal argument and persuasion about what

should and shouldn't happen at this level on a rewrite. I do however permit myself one observation. The whole examination process has taught me to be wary of trying to be too innovative in style and I am definitely conscious, as I rewrite this thesis, of slipping back into the traditional academic formats of critiquing and scholarship in order to complete this sort of work. As I do so, it leads me to start asking questions. As my level of critique rises once more, am I once again going to be prevented from seeing unexpected data, new levels of inference and interpretation, novelty that was once denied to me by my overdeveloped positivist ontology, from which I have struggled to escape? It illustrates the delicate balance that exists between being able to infer at a high level of critique and at the same time remain open to innovation. As I develop as a researcher, I also remain aware that I should not necessarily be seduced by constructivism in the same way I was seduced by positivism. By overtly eschewing a quantitative perspective in favour of a qualitative one, I have stepped outside typical behaviour as an ENT surgeon and possibly 'transgressed' the arena of acceptable values. Such transgression is neither a "denial of existing values and the limits corresponding to them nor an affirmation of some new realms of values and limits" it is a "contestation" of values that " carries them all to their limits." (Cutting 1994 p22) Such 'transgression' is, according to Foucault, "an affirmation of human reality, but one made with the stark realisation that there is no transcendent meaning or ground of this reality.....Transgression is essentially tied to intensity...and is a direct consequence of transgression." (ibid)

With this backdrop in mind, it is time to start the main body of the thesis.

INTRODUCTION

Decision making-what I mean by the term

The description 'decision making' is a wide, ill-defined phrase that incorporates many different ideas of what is meant by the term. The purpose of this first section is to make clear what aspect of decision making I propose to research. This clarification also includes a brief discussion of those aspects I have chosen to exclude. To emphasise this I have undertaken a brief review of the more conventional approach to decision making in clinical practice, for example the use of mathematical models, computers, algorithms. Finally, there is the mandatory section on how this thesis is presented in format and style and I have taken this opportunity particularly to emphasise the problems associated with trying to convey a change in practice by the use of the written word. With this in mind I have considered the various audiences for which this is written.

What is this thesis about

The initial purpose of the thesis was to find a series of frameworks that permitted me as a doctor to practice medicine in a scientific and well informed manner but enabled the patient to influence, shape, control or take charge of the decisions in an authentic way. Of course, it could be argued that every doctor should be striving to achieve the same objective, so why was I choosing to make this the subject of a detailed study? The short answer is that it is not easy to do this every day, with a variety of problems, and with each and every type of patient a doctor would be expected to encounter. The problem in trying to do this is encapsulated in the minor title of the thesis; 'Relating the Science of Discovery with the Science of Implementation'. What then is meant by the terms 'Science of Discovery' and 'Science of Implementatio

I accept that there exists within medicine a core body of scientific knowledge and, like many, am interested in extending, developing and refining this core knowledge within my specialty. I undertake conventional scientific research, regard it as important and enjoy it. I use the term 'Science of Discovery' to describe this process. As I became increasingly better informed about my subject at a scientific level, it was clear that non-scientific influences that should form an important part of any decision, were becoming increasingly marginalised. For example, it should be important to understand the way patients would interact with me as a doctor, man, married man, family man, even family man with children who had undergone surgery in explaining how certain decisions relating to surgery were reached. So that it was not enough in itself to have the requisite medical knowledge because the process of applying such knowledge was a science in its own right; this is what I mean by the term the 'Science of Implementation'. This science of implementation was a different kind of science; it wasn't the ordered, logical kind of science I was used to considering. It certainly was not taught to me or, to the best of my knowledge, to anyone else as part of the curriculum for undergraduate or postgraduate medical education. I, for one, had qualified as a doctor assuming that decision making was a process akin to that depicted in **Figure 1**, instead I was finding that decision making was much more akin to the process depicted in **Figure 2.** When I began examining my reasons for making certain decisions, they didn't seem to make sense, at least not *logical, rational* sense.

At first sight there seemed to be only two outcomes. Should I compromise the scientific element of my medical practice and remain a 'realist'? Alternatively, should I compromise the humanistic side of my medical practice, the art of medicine, and continue as a technical rationalist? Neither of these possibilities seemed acceptable so this thesis became a personal search for a model or models that allow the science and art of medicine to work together more satisfactorily. It is about a search for a framework that enables me to remain a scientist but practise as an empathetic doctor. It is about finding a 'science of implementation' to work with rather than compete against a 'science of discovery'.

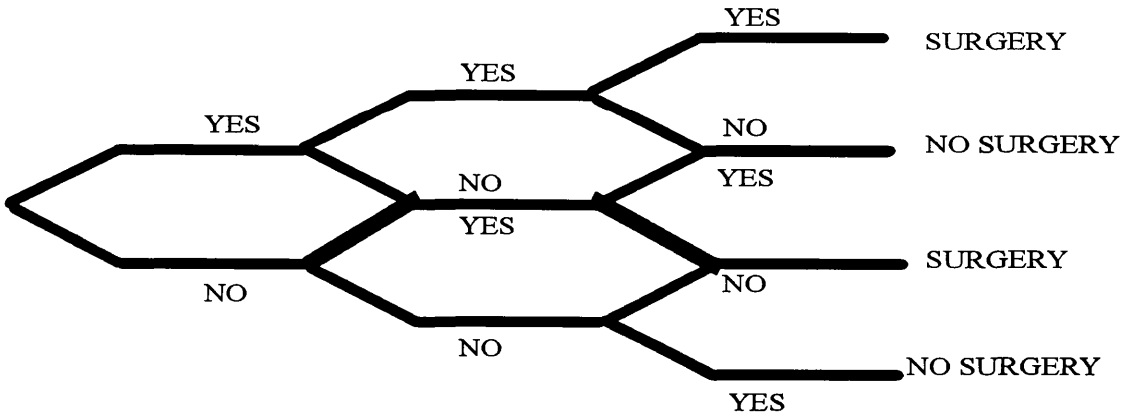


Figure 1
Conventional clinical decision making trees look like this and suggest that the process is neatly structured.

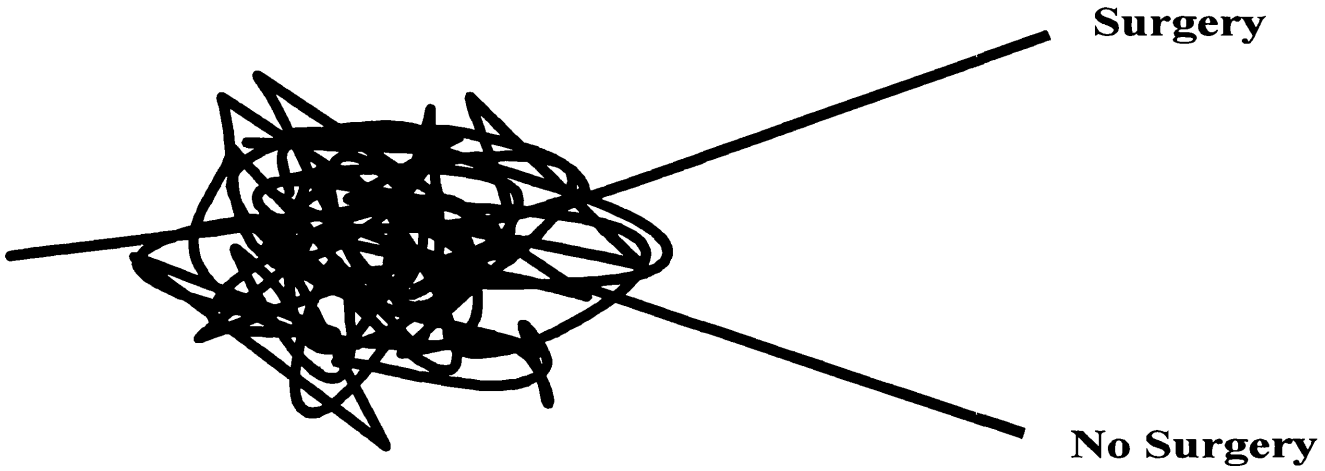


Figure 2
Quite often decision making in the clinic appears to be more like this !

For the patient, I hope, this thesis is also about providing a series of frameworks that permits a flexible degree of empowerment over which they have some control. This is not as straightforward as it sounds. The currently popular model of patient empowerment is based upon a 'consumer model of rational choices'. A doctor is encouraged to provide a series of options, together with their advantages and disadvantages, so that the patient is able to make an appropriate choice. A doctor who fails to do this properly, or who encounters problems when acting in an intentionally benign, directive manner, is becoming more likely these days to find themselves the target of litigation. So adherence to this consumer model can also mean that doctors are sometimes reluctant to make more directive suggestions for treatment, fearful that they might unduly influence the patient and be subsequently open to criticism. I certainly recognise that patient empowerment based on choices is an important model to consider but I find that if I practice this way all the time, I know that I am being less effective, less useful for the patient. Besides, as I will discuss later, there is evidence that when medical practitioners become patients they do not generally wish to be offered choice. They will frequently seek out an expert and take the advice uncritically. It suggests an instinctive understanding that something is lost on being offered choices in this way. This sounds as if I am interested in producing a charter for doctors to take control once more over the doctor patient relationship, but this is not my wish at all. I am seeking a different position. I am seeking a state of *mutuality*, when both the doctor and the patient can contribute to the medical input with equal status. From the research perspective, the challenge was to do this without setting quantitative and qualitative traditions in opposition to one another except as a dialectic to generate understanding. One was looking for theoretical triangulation.

"Theoretical triangulation embraces multi-theories and breaks through the parameters and limitations that inevitably frame an explanation that relies on one theory. It recognises complexity and diversity and that multiple realities exists."
(Banister, Burman, et al. 1994, p145-149)

It meant looking for a practice enriched by theoretical triangulation so that one used both positivist and qualitative perspectives in deciding what to do. This would hopefully increase the degree of context richness. Of course a constructivist would argue that this is nothing more nor less than disguised constructivism but this is a position that I will address later in the methodology section.

What this thesis is not about

Because the term 'decision making' is such a general term, it is necessary to state clearly those aspects of decision making I have chose to exclude. This is particularly important because most of the medical literature on the subject reflects those aspects of decision making that I have deliberately chosen not to study. These articles fall into two main groups; the use and selection of medical information to make decisions and the use of algorithms or computer driven programmes to assist decisions.

First of all, this study is not about the use or selection of medical knowledge to make decisions. It is not therefore about evidenced-based medical practice or an analysis of the medical thought processes that take place to make a medical decision. Secondly, it is not about the other general area of decision making; decision making trees and computer based programmes to assist in making decisions. In the past few years there has been a profusion of articles in the medical literature adopting this approach and being of a mathematically inclined type I have found myself reading them. This has made me aware that there is an element within the ideas presented here that is mathematical, mechanistic and sequential in nature and this is evident in the diagrams used later in the thesis to summarise the different frameworks.

Both these general areas of decision making research are useful and interesting and I do draw upon some of these ideas in day to day medical practice. This is the tradition from which most doctors, including myself, will emerge and represents the quantitative end of the spectrum that makes up decision making. Because this thesis sets out to explore in a

qualitative manner the subject of decision making, a brief review of the traditional medical approach to the subject would be important as part of the background from which I was educated and from which this study emerged.

Traditional decision making

In a review of the literature, I found 67 articles on the subject of clinical decision making in the years 1970 to 1980. In the following ten years, from 1980 to 1990 the number had risen to 379 (source Medline Silverplatter). Virtually all were analytic in approach with a focus on bivariate relationships which are generally assumed to be linear and causally unidirectional.

In the earlier years 1970-1980 articles on decision making fall into a number of broad groups. There were those based on the use of computers (Black, 1980. p91-8; Murray, 1977. p262-4; Card & Mooney, 1977. p1627-9; de Dombal, 1979 p33-57; Gorry, 1973. p45-51; Gleser & Collen, 1972. p180-189), and others with a more economic interest in mind particularly with respect to the allocation of resources. (Card & Mooney, 1977. p1627-1629; Nagurney et al, 1979. p727-736; Crane, 1975. p1-33; Pauker & Kassirer, 1975. p229-234), It is possible to detect the beginnings of a process in which the authority of the doctor to decide is questioned (Baron, 1979. p337-365; Anonymous. Ed., 1975. p191-2; Vertinsky et al, 1974. p121-134; Klein, 1978. p73-74; Schoolman, 1977. p103-5), and nearly all of them look at clinical decision making as a series of logical steps, "branching chain logic" of the kind depicted in **Figure 1** to resolve problems in a logical stepwise fashion. (Holmes, 1979. p1131-8). The nature of the doctor patient relationship was examined, particularly the contractual nature of it (Burke, 1980. p615-624; Baumgarten, 1980. p180-4; Churchill, 1977. p129-132) but no real interest was shown in the way that qualitative factors came to influence decision making.

In the 1980's papers using computer methods continued to develop (Fryback, 1986. p27-33; Carpenter, 1986. p843-850; de Vries & de Vries Robbe, 1985. p57-64; Kassirer et al

1982, p251-9; Pauker & Kassirer, 1981. p1831-7) but reservations about their widespread application were voiced. Sadler expressed the view that it was important to write your own algorithms in order to reflect your own philosophy and clinical practice and not rely on algorithms developed by others (Sadler, 1986. p545-7). Most of the work produced on the subject tended to be more interested in the use of computers in the diagnosis, or medical management where large amounts of data are required (Pauker & Kassirer, 1981. p1831-7; Sher, 1980. p420-3). Fryback developed programs that handled uncertainty and Kassirer and colleagues collected as verbal transcripts the thoughts of experienced clinicians to formulate theories that were embodied into computer programmes. Again these programmes only looked at the way physicians handled information in reaching a diagnosis. An important medical educator of the time, Laurence Weed, pointed out that it was important not to overlook the fact that there were many variables in the whole process of decision making that were only known to the patient and unique to them. It was important that patients had a more central role in the process of medical care (Weed, 1986. p55-79). In a sense the same dilemma preventing pure science being directly applied to clinical situations in a humanistic fashion that I encountered in my own practice emerged in those trying to employ computers. A clue to this can be found in an early article in 1972 on the use of computers in medicine, which concluded that;

"clinical diagnosis contains a large element of 'pattern matching' and that diagnosis that could not identify such patterns would be "ineffective in roughly one third of all cases of acute abdominal pain."
(Staniland et al, 1972. p393-8).

In the literature today, articles about decision making have become much less common. As the rhetoric of health care has changed, they have given way to articles about purchasers, providers, allocation of resources, costs. This approach has become possible as computers have permitted the handling of vast amounts of information to enable these problems to be addressed. Perhaps that is, for the moment, the true role of computers (Schon 1983 p43). The problem of handling qualitative data, recognising patterns, analysing bias, judging the

non scientific elements of a situation that I encountered in medical practice and discuss later cannot be solved by this approach.

Finally, because analytic clinical decision is broadly mathematical in approach, it may be more than coincidence that this interest in clinical decision making coincided with the development of the computer. Not only have computers looked at the decision making process, they may also may have been highly influential *in the way* that the decision making process has been regarded. As well as their use as a mathematical tool, computers have influenced thinking in a more subtle way. In 1978 Microsoft launched it's operating system, DOS and five years later

"even popular science spoke of health as the state of a biological system"..... "Systems analysis fostered new notions of and practices in healthcare, but also surreptitiously affected people's perceptions of themselves."
(Illich,1995. p1652-3).

The language of computers became incorporated into the language of healthcare. The metaphors of computers became some of the metaphors for health. In the 1950's a definition of death was based on cessation of the heart, extinction if you like of the emotional centre of the body, but in the 1990's a definition of death was based on the cessation of brain function, extinction of the intellectual *computer* centre of the body. Perhaps this simple redefinition of death, and by implication life, encapsulates the shift from emotional to rational approach to medicine, influenced, I suspect, by the introduction and use of computers.

Format of the thesis and the style of composition

There is a fundamental problem that I have to address. It is the question of how to convey a change in practice by the use of written descriptions. I have attempted to tackle this

problem by attention to three aspects. The format of the study, the techniques of argument implicit in the writing style and finally by recourse to Aristotle.

The format of the thesis is essentially narrative in style in that it broadly follows in historical sequence my change in understandings. I am aware of the risks in presenting my work in this way but felt it important to draw attention to a number of things. I have done a fair amount of conventional medical research and know that when preparing the manuscript some 'cleaning up' of the data and arguments takes place, which whilst necessary when submitting work for a journal, nevertheless removes some important information. For example, changes in behaviour do not always follow a logical series of steps and so the progress towards change is not presented logically. There is a randomness about obtaining insights into your own behaviour and utilising the narrative methodology gives insights into the uneven nature of such progress. Nevertheless, when preparing the thesis and presenting it as a narrative I have tried to be aware of an underlying structure.

Conventional	**This Thesis**
Introduction	**Introduction**
	Scene Setting
	Catalyst for Research
	Acquiring the Scientific Basis of Medicine
Research question	**Medical Knowledge**
	Extending the Meaning of Medical Knowledge
Methodology	**Methodology**
Results/Discussion	**Reflections of Clinical Practice**
Conclusions	**Frameworks for Clinical Practice**
	Some Conclusions and the Future

It should be noted that much of the discussion is interwoven throughout the results section. This approach is consistent with my practice because reflection in action is about sense making in the moment, not afterwards. In addition because the methodology

evolved as the study developed, these moments of change are indicated throughout the results section. This, I would argue, is consistent with the emergent nature of qualitative inquiry,

With all this in mind I would next like to consider the techniques of argument. These techniques of argument exist at both superficial and deep levels. At the surface level, the archaeology of argument loosely follows the conventional order as already mentioned. The deeper arguments lie within the sentences and are dependant on the use of "active or passive forms, positioning of adverbs, the choice of first or third person, referencing patterns" (Horton, 1995. p 985-6) and I have been less analytical and more intuitive in my selection of these influences. An editor when preparing articles for publication would demand a uniformity of style, of choice of first or third person, present or past tense etc. which creates a slightly bland but authoritative and 'objective' style. It seems to me that this was inappropriate when presenting a research project of a more personal nature such as this. I have therefore utilised the first or third person, present or past tense whenever it seemed appropriate and the importance of preserving this freedom has recently been raised (Heath I. 1996)

These deeper arguments are also dependent upon referencing patterns. The medical literature will by and large draw upon a body of references that frequently refer to one another and do not often dip into other philosophical schools of thought. I really noticed this in my database of conventional medical references obtained from Medline. There are few references to be found from the qualitative schools of research in any of these quantitative studies. For example, from 116,000 'hits' to the search word 'surgery', 434 included the keyword 'qualitative'. I have tried to break away from this world of mutual referencing. For example I have used references from everyday life, from the television, from radio, the newspapers, from books that caught my attention. I have not attempted to, or wished, or even could be exhaustive in this respect given the rich nature of data available. For these reasons, there may be, from time to time, a style that may be incongruent but I have attempted no special analysis of this. This is probably largely due to

the timescale of the project being, as it is, set over a six year period and is most evident in the diary sections. Even when it is obviously present, I have left it as it is.

Despite my attempt to try and present a change in practice in a convincing manner, I recognise, as others have done, that this may be an impossible task to accomplish. Perhaps this can only be experienced by witness.

"Practical Knowledge, knowing how, is the consummation, the fulfilment, of the knowledge quest...for a skill, knowing how to do something, can never be reduced to written descriptions of doing it."
(Heron,1996. p21)

In the end it may be necessary to draw upon Aristotle for support. Aristotle provided insights into the rules of the style of composition when he grouped proofs into one of three types. These were a presentation of the arguments themselves; secondly, the character of the author, who should be seen as fair-minded and balanced in outlook; and thirdly, the emotional state of the reader. All three can be appealed to by speculations about the clinical importance of the results and the implications for future research. I am happy to be judged by these criteria but this research is principally for my own benefit and I hold no illusion regarding its importance beyond my own personal experience. As a trainer of future surgeons I am in a position to influence them, so that I have taken the opportunity to formally present this work for external review. Of course this immediately raises the final question of this section. Exactly who is this thesis for?

Who is this thesis for? Who are the audience?

I am aware of three separate audiences, each with different perspectives, who have to be considered when preparing this work. These three audiences are myself, the University and finally other doctors, who may wish to read it. I will consider, for a moment, each of

these audiences and how it has been necessary to modify the thesis to accommodate these different audiences.

For myself it is an opportunity to carefully consider my assumptions, to organise, to refine and clearly define my ideas upon the subject of 'decision making'. It is a personal statement of how I see the way that I practice. That had been a relatively straightforward task. I am conscious, when presenting this for academic view, that it is evaluated not as a personal statement but as a work in relation to other published works. Because I am using the perspective of one academic department, the School of Management, to look at the activity of another, the School of Medicine, assessing the work in this way might be problematic. Against what body of work is this thesis going to be compared; previous work on decision making from the world of medical practice, ideas from the world of management or both? I have tried to maintain a balance between these two different perspectives by selectively drawing texts and references from both Schools. In effect the work occupies the middle ground between these two disciplines. It is difficult to defend such middle ground and from both perspectives my use of the literature might appear superficial. I would accept that criticism but would wish to make one observation. I started out with a 'gut' feeling that it would be interesting to undertake a study of one discipline from the perspective of another and in my experience this approach has been rewarded. What I have learnt from this study is that with only a modest understanding of issues such as 'power' from an organisational perspective it is possible to acquire valuable new insights into medical practice.

I would be disappointed if this attempt was interpreted as naive, because throughout the thesis I have also had to bear in mind that at the end of the day I am a practising doctor. Any work written by a practising doctor has to consider its the final audience, that of the medical profession. In considering an audience of doctors, it seemed necessary to draw upon the traditional literature of medicine so that this point of view is to a degree acknowledged. Doctors are suspicious of managerial theories and jargon, which is ironic given the extensive use of theories and jargon in medical life, so it seemed necessary to be

careful about the use of these. Nevertheless, I hope to convey some of the fascination that can be experienced and usefulness that can be achieved by only a modest understanding of organisational theory. This point obviously touches on the subject of generalizability. At the heart of positivism is the idea of the grand solution and it is important to distance myself from such an idea. The place of generalizability in the qualititative methodological literature appears to be that it is unimportant, unachievable or both. Nevertheless, I would hope that the concept of generalizability is best thought of as 'fit', which others see as relevant enough to consider the possibility of applying concepts and conclusions of this study for themselves and of course in their own way. (Schofield 1993. p200-225)

It would be my hope then that something in what I have written would trigger their interest to start and consider the same issues that I have done and in doing so move the ideas forward. In this respect the 'fit' has to be seen from the medical perspective as well. Whilst I have not formally tested the degree of fit yet with my colleagues, I would claim a general awareness of what would be generally acceptable and what would not.

So what then stimulated my interest to consider all these issues? How did I come to collaborate in a research project between a Department of Postgraduate Medicine and a School of Management to consider decision making? What was my catalyst for research?

CATALYST FOR RESEARCH

Introduction

This section explains what triggered my interest in decision making and why it became necessary to find an alternative definition of what constituted relevant 'medical knowledge'. **Trying to be a scientist in a medical setting** commences by explaining what happens when I tried to practice medicine in a way that was more and more 'scientifically rigorous' in a clinical setting. It became increasingly difficult to do so in a way that paid attention to the context in which the problem was set. The choice appeared to be one of either continuing to practice as a scientist and ignore the context or alternatively pay attention to the context at the expense of the science. In **Relating the science of discovery with the science of implementation** the problem is seen in terms of finding a new science to manage within a suitable framework the traditional science of medical practice. Finally, in **What sort of frameworks are needed?** I conclude with a discussion of the kind of framework or frameworks that are needed to accomplish this.

Trying to be a scientist in a medical setting

My medical training had taught me that medical science believes that health and disease can eventually be completely understood in terms of a set of scientific, medical principles. These principles are derived from a process of observation, measurement, induction, hypothesis formulation and testing claiming to be in the positivist paradigm. This means that the term 'positivist' is used to describe a medical practice built on a foundation of 'evidence' based data of the kind produced by a methodology of randomised, double blind, controlled clinical trials. Each new set of data allows these principles to be understood in greater and greater detail. Each research contribution allows us to more closely approximate to a reality where health and disease is completely understood and so it appears that all that is needed is sufficient effort to complete the task. Eventually the

knowledge produced by this positivist approach reaches the point where 'victory' over disease is complete. This rationale leads to a belief in the supremacy of the positivist approach. However, in day to day practice, it is acknowledged that clinical medicine cannot be a precise science, which suggests a post-positivist position, nevertheless one that still regards positivism as the ultimate, regulatory ideal. My own role in all this appeared to be clear. As a scientist and doctor I was invited to make a small contribution to this overall understanding. Perhaps with luck I would write a definitive sentence in the definitive paragraph of the definitive chapter of the definitive book.

To begin with this idea was sustainable. The process of accumulating knowledge through postgraduate exams together with research that all trainees are obliged to do created the impression that I was starting to make my own particular contribution. After a while this approach became difficult to sustain. I clearly remember one case in particular when I began to seriously challenge this perspective. About one year after I had qualified I was doing a locum in general practice and was asked to see a young child with earache. It was about midnight when I arrived and the child and the family were in a considerable distress. Contemporary medical literature was starting to make the point that it was unnecessary to treat an infection of the middle ear with antibiotics. Practice based upon strict adherence to scientific principles would advocate that antibiotics should not be prescribed in this situation but I 'felt' I could not leave the family without giving the child some penicillin even though the 'evidence' pointed to the fact that this was unnecessary. There appeared to be no means within a positivist ontology to be able to consider the question of context when, as I saw it, context played a deciding role in what was to be done.

What struck me at the time was that in all the studies I had read about ear infections, the context of the medical problem was never acknowledged as important in determining the need for treatment. Indeed great efforts had been made to exclude the question of context by formulating it as 'bias' and hence inadmissable in the analysis of the problem. I had chosen to follow a paradigm that excluded context.

"In the most general terms positivism is a collection of prohibitions concerning human knowledge, intending to confine the name 'knowledge' or 'science' to the results of those operations that are observable in the evolution of the modern sciences of nature." (Kolakowski 1993. p7)

However, the extent to which I had been paying attention to the role of context in science was not an all or none phenomenon. There was a range of activities that gradually paid regard to context. Work has shown that a doctor faced with a patient suffering from, for example, malignant disease will contemplate a hierarchy of progressively less positivist options. They will order detailed x-rays (scientific experiment); obtain information from previous studies (controlled trial); perhaps organise a trial of chemotherapy to see what happens (quasi experiment); make use of various diagnostic algorithms (system aided judgement); seek an opinion from a multidisciplinary head and neck clinic (peer aided judgement) and perhaps obtain an opinion based on experience from his principal physician as to whether or not he will 'do well' (intuitive judgement). (Hamm, 1988. p87). The process will be constantly shifting up and down this continuum and in practice does not mean choosing one particular mode of practice and sticking with it. The closer the selected mode of inquiry was to 'scientific experiment', the more analytical, visible and structured it was and perhaps more accessible to understanding by an outside third party. Consequently, research on the usefulness or otherwise of investigations such as x-rays or systematic reviews of controlled trials are relatively commonly encountered. Research on 'intuitive' judgement is, in contrast, relatively rare. In order to make medical judgement more visible and hence accountable, there has been a tendency to try and evaluate system aided, peer aided and intuitive judgement in more positivist terms. The resurgent interest in 'evidence based medicine' is one testimony to the increasing importance of the outside third party in shaping and influencing the doctor patient interaction to be more scientific in this way. As I will later discuss, all this may be part of the increase in the practice of surveillance that seeks to make individual discursive practice more visible.

In the twenty years since I have been qualified, the traditional science based medical literature is beginning to acknowledge that all practice cannot be positivist based. Furthermore, by ignoring the place of, for example, 'intuition' it can mean the loss of useful information. The idea that intuitive judgement takes place much of the time is one that few would question but only occasionally will medical journals report an attempt to examine 'scientifically' such phenomena. In a recent example, surgeons were asked to predict the outcome of an operation according to 'gut feeling' and this was compared with a scoring system to quantify risk 'objectively', the POSSUM (Physiological and Operative Severity Score for enumeration of Mortality and Morbidity. (Hartley & Sagar, 1994. p277-8). The study showed that surgeons intuitively assessed outcome rather well. It may be 'unscientific' to approach a problem like this using an intuitive parameter such as 'gut feel' but it was surprisingly accurate in it's application.

If surgeons are beginning to acknowledge the importance of intuition in decision making, is there a need to consider the intuitive judgements of patients? There is also the question of context in which the whole problem is set and here there appear to be many factors to consider. They include factors such as age of the patient, previous experiences with treatments by doctors and by other healthcare workers, acceptability of treatment, compliance, cultural factors, expectations, need for information, mental state, social and family circumstances, place within the family, interpretation of problem by the relatives, impact of problem on the relatives. In addition there is the importance of clinical setting including the role of room size, room layout, chair size, dress code of doctor, and presence of others in the room. Then there are those factors pertinent to the doctor such as communication skills, previous experience, expertise skill and lack off, mental health, workload, relationship with other health care personnel including referral source, uncertainty, time factors, time of the day, day of the week. How then does a doctor develop a scientifically based practice and at the same time pay attention to all these and the many other parameters too numerous to mention?

It has been said that we explore the world through experience, reasoning and research. Experience may be personal, or give way to authority such as books or teaching and reasoning may be deductive or inductive or inductive/deductive. (Cohen and Manion, 1989. p4-9) I had tried to research the problem of trying to apply findings I had obtained from the medical literature in my own way. Like many other doctors, I suspect, I had undertaken this in a clinic in a self-regulating and self-referencing manner in the hope that resolution of this problem would be obtained by experience. Such an approach suggests a passive response to inquiry in that answers come 'with time'.

Such an approach can lead to "an uncritical acceptance of authority opinion and an over dependence upon personal experience." (Cohen & Manion 1989 p5) Because such a critically naïve approach is systemic both within one's practice and within the system (all doctors sit in clinics isolated from one another after the first few years of training) what are the alternatives open to a doctor?

One solution may be to pursue a career in which this dilemma is less apparent and this particular strategy is briefly discussed later. Alternatively, it may be necessary to embrace a new perspective, a new way of looking at the problem and throw the process open to external review.

Relating the science of discovery with the science of implementation.

In summary, in developing a scientific foundation for clinical practice I had been encouraged to control or 'eliminate' unwanted bias when undertaking research but later it became necessary to accept the importance of all this 'bias' when medical facts were reintroduced into context. This has been identified as the gap between "*the sciences of discovery and the sciences of implementation.*" (Jones R, 1995. p2). Thus the practice of clinical medicine carries with it the difficulty of trying to work within a positivist paradigm, paying attention to all the published work, and at the same time acknowledging the existence of other qualitative factors that cannot be ignored. The appendices at the end

of this thesis are transcriptions of interviews made with three patients, David, Patrick and Valerie. These were made in order to explore the role of non-clinical issues such as power, 'gut' feel and others that impinged upon the decision making process. Each one of them had to make difficult decisions about their treatment. How does David decide whether to leave his sinus tumour untreated so that in the short term he can enjoy and active life or take a risk and opt for extensive surgery in the hope of a small chance of a cure? (Appendix 1) How does Patrick decide if he should accept medical advice and have radiotherapy after his operation or follow his instinct and leave well alone? (Appendix 2.) How does Valerie decide whether she should have a heart and lung transplant or not? (Appendix 3).

Even a viewpoint that accepts some role for non clinical processes in conventional clinical medicine, simplifies the reality encountered in a clinic. What should be the response on encountering a patient with an entirely different medical ontology to that of Western medicine? A positivist description of disease and treatment doesn't always make sense to someone whose world view is based upon 'natural explanations' of disease and treatment utilising for example homeopathic treatments, or diet treatments or Eastern medical perspectives. This position alone certainly challenges one assumption of positivism, that is the belief in the unity of the scientific method. (Kolakowski 1993 p2)

Whatever paradigm is adopted, there is the need to manage the potential tension produced by such differing points of view, the view of the doctor and the view of the patient; the tension produced by a positivist and hermaneutic perspective. In the end it needs a framework in which qualitative and quantitative processes can operate so that it may become an exploratory device of use to both parties.

What sort of framework is needed?

The interest for me came in trying to find a framework to behave in a way that pays attention not only to scientific principles but also places the medical problem properly in

context. By this I do not just mean context in the sense of positioning the medical problem in everyday context such as occupation or lifestyle but the *context* of the context. This means developing an awareness of the cultural and historical context of medicine, how this has influenced the way that language has and is used to convey meaning and the way that medical power has come to be used by the actors. The challenge is to accomplish this without managing to disempower the patient further by becoming an even more sophisticated manipulator of other people's perspectives, a criticism that has occasionally been levelled at certain kinds of qualitative research. In order to effect a radical reappraisal of what I believed, it became necessary to examine the way I had acquired my own knowledge and how in the process of acquiring it, I had chosen to believe in certain things and not in others.

ACQUIRING THE SCIENTIFIC BASIS OF MEDICINE

Introduction

The previous chapter highlighted the problem encountered by strictly adhering to a scientific medical practice based solely upon positivist principles. Such a medical practice will regard as relevant to the decision making process only certain kinds of knowledge and data. How did I as a medical student come to adopt this approach? In the sections, **Early development and schooling** and **Medical School**, I examine how I have come to 'frame' certain information to regard only that knowledge as relevant, as scientific, in the pursuit of good medical practice.

I notice the effect of increasing specialisation in focussing on problems in a smaller and smaller aspect of body function, which seems to make the problem of considering context even more difficult. In **Making choices; careers and consultation styles** I suggest that this 'problem' may be side-stepped by pursuing a career that is technical and non context based or context based and non scientific. Choosing to pursue a technical specialty and pay due regard to the importance of context meant reappraising my ontology to permit other ways of seeing the world. This change needed an appropriate 'jolt' or insight and this moment is described in **Intuitive Knowledge as science.**

Early development and schooling

The development of a positivist epistemology in medicine is very much helped by discarding those issues, many of them qualitative, that do not seem to fit in with the idea of positivist sense making. This means making assumptions about what is and what is not

important to regard as data and it is these assumptions that "make messes researchable; often at the cost of great oversimplification, and in a way that is highly problematic." (Morgan 1983 p377) The process of discarding and disregarding certain items is done in the interests of clarity and neatness and this process is part of the characterisation of medical knowledge. What does this mean in practice? It might mean, for example, disregarding the patient's interpretation of what is wrong simply because the idea is not expressed in medical language. Alternatively, it may involve the wholesale disregard of medical healthcare systems that have stood the test of time for thousands of years such as acupuncture. This is an interesting example because it illustrates how a practice (acupuncture), previously marginalised, only became accepted after it was re-framed in the positivist paradigm. Acupuncture, as a form of treatment was completely disregarded by the conventional medicinal establishment until the early 1970s when the 'gate theory' of pain control outlined by Wall provided a positivist basis for why it should work. After this discovery, acupuncture became much more acceptable.

This process of discarding data that does not fit into a particular belief system I see as starting from early on in life. I illustrate this by a small event that occurred one day when I was with Laurie, my son then aged one year. We were playing together when he suddenly stumbled across to a waste paper basket and picked out a piece of paper. It was a shiny coloured cellophane wrapping of the kind that is used to cover a small present. This piece of paper was reflecting brilliantly as it caught the sun shining through the window. Whilst I had noticed this beforehand as it lay in the waste paper basket, it wasn't until he started studying it carefully that I saw it as an object of interest. Because the piece of waste paper was in a *waste paper* basket, I had automatically categorised it as 'waste paper' and therefore not worthy of attention. Without this preconception, Laurie had seen it differently and saw it for what it was as an unusual and interesting phenomenon. My immediate instinct made me want to take the piece of paper from his hand and throw it away again but instead we decided to look at it carefully together. It was a prosaic everyday reminder to evaluate carefully what is being disregarded but in principal was no

different to an occasion when years later as a researcher I took a second look at some data that had been 'thrown away'

I had arrived at Toronto University in 1985 as a Fellow in the Department of Surgery with an international reputation for a particular kind of operation. This reputation was founded on the good results obtained in the removal of a rare type of brain tumour. Over three hundred of these had been performed in the previous four years and analysing the results of this operation would be of great interest to many other centres and certainly worthy of publication. Naturally I offered to undertake this retrospective analysis only to be informed that the Fellow from the previous year had chosen to undertake this. All that were remaining from the complete set of case notes were the twenty patients left out of the study because they had been considered too old for surgery. They were categorised from the medical standpoint as belonging to the *'waste paper basket'*. They were not of medical interest because they were patients in whom treatment was not being contemplated. My initial disappointment gave way to interest when I appreciated the possibilities in studying the outcome of a group of patients whose tumour remained untreated. How quickly did it grow? What were the complications as the tumour grew? These were important unanswered questions for patients, particularly the elderly, but perhaps not obviously so to a medical profession orientated towards treatment and treatment success. So that for good reasons it was important to look at such a group and the study revealed that the untreated elderly patient did rather well. (Nedzelski et al.1986).

This simple illustration of the 'discarded notes' makes one consider the way that patients are represented by certain kinds of data. The medical representation of patients is in the form of notes. This privileged space in medical terms is a *representation* of the patient in the form of a disease profile. In its capacity to represent it is nothing short of a medical art form, a piece of medical art work (Flynn 1994). In hospital organisations, patients are represented by their notes and I have witnessed the distress in patients when the notes are lost and on these occasions patients are made to wait until their *identity* is found again. This representation is also an interpretation, a conventional positivist interpretation, of the

medical condition. This means that notes convey both representation and interpretation. Whose interpretation? It is an interpretation of the medical staff and this may explain why it is usual for patients to be denied access to notes; the phrase "Not to be seen by the patient" is written on the front cover. The unilateral nature of interpretation made in the notes and the lack of access to these notes by others might go some way to explain why the notes of the untreated group remained un-researched. It does not appear to be common practice to ask a group of patients with a particular condition what they would like to be researched. If it were, I suspect it would not have been long before some patients with brain tumours would have wanted to know the results of 'no treatment'.

Hospital notes also demonstrates a contingency approach to data; it is neat and generally manageable data. It has taken me many years to appreciate that in the process of acquiring data, whether it is in the form of history taking, examination of patients or examination of data, there is a process of discarding data that doesn't seem to fit. In fact this process is institutionalised. Controlled studies will clean up data in this way, calling it bias or qualitative data. Indeed the language of statistics used to assess data echoes this with words like Fishers *exact* test, *linear* regression etc. Where do we get this desire for neatness in results and why did I find it so satisfying to produce work that was neat in this way?

At school there appeared to be an emphasis on precision, on exactness, on neatness. This neatness was both explicit and implicit and this implicit neatness it seems to me is part of the positivist paradigm that educates you into believing that solutions are precise. For example, I learnt to know when an answer was correct because it became possible to 'feel' when this happened. I see this in simple examples as I help my daughter Rachael with her homework. The awkward sum:

5.037 divided by 1.679 becomes the neat answer = 3.

The correct answer is neat and exact. There are no 'fuzzy' edges around it. This exactness, neatness and resolution of form is used to convey subtly to the student that the answer is correct. It didn't take long before I began to believe that all answers in science have this neatness of form. In the end, I started to analyse, be critical of, and reject certain 'unscientific' facts in order to adhere to this neatness of form.

Medical School

In medical school the idea that solutions were neat, describable, positivistic was transferred from mathematics, physics and chemistry to the human body. The early part of medical school began with an introduction to anatomy, biology and physiology. Apart from the strange surprise at discovering that we are after all just like animals below the surface I began to see in the human form a collection of individual components. We appeared to be made up of levers, of pulleys, of servos, of engines, of pumps, of shock absorbers and of filters. In doing so gradually I began to abandon the idea of regarding the human form as a single entity.

This way of teaching medicine may have had an underlying purpose. Prior to about 1800 disease was classified as *species* with no necessary connection to the body. Diseases were perceived as transferring to the body when their qualities are in line with the patient's temperament. This spatialisation of illness was conceptual so that disease was ordered hierarchically into families, genera and species in terms of analogies and resemblance. The patient was a potential obstacle to the perception of the disease. After 1800, clinical medicine was to see the body as the natural space of the origin and distribution of disease; a space determined by the anatomical atlas. Anatomico-clinical theory was developed where disease indicated lesions in specific tissues.

Contemporary medical teaching reflects the way medicine organises itself to form medical knowledge. So that at one level the purpose of anatomy dissection was to assist learning about muscular and bony form, the position and relationship of various organs, but at

another it also resulted in a shift from a holistic view of human form to a mechanistic, classical science view of human form. This sense of positivism was reinforced by mathematical concepts such as Fourier analysis of anatomical forms in biology, physical concepts such as partial blood gas pressures in physiology and chemical concepts in biochemistry. As attention was focussed upon acquiring knowledge of a certain type, attention was diverted from what is being overlooked. What was being overlooked were the assumptions of positivism. These are determinism, empiricism and the principle of parsimony (Cohen & Manion 1989 p18). Determinism assumes that all events have causes. Empiricism pays attention to that which is verifiable by observation and experience. Finally, the principle of parsimony states that if a phenomenon can be explained by two laws rather than three, then the more economic explanation is accepted. These assumptions are carried over into clinical practice. The role of observation is continually emphasised in outpatients, the ward, the theatre and the post-mortem room in order to find the cause of the disease. The principle of parsimony expresses itself in the notion that a single diagnosis is sought to explain all symptoms and signs even to the point where multi-system disease is grouped under an all embracing diagnosis. I am not arguing at this stage that the principals of determinism are inappropriate, just that they carried with them these assumptions that circumscribed the way I was being taught to consider what was data and what was appropriate analysis.

Yet even within this scientifically based framework of medical education, there were moments when I realised that it became unsustainable to believe that everything could be described in this way. An example of this arose in considering brain as nothing more than the equivalent of a large computer. The term 'fuzzy' had been applied to a kind of logic by Zadeh some six years previously in an engineering paper called 'Fuzzy Sets' (Zadeh, 1965. p338-53) and was brought to my attention by a mathematical friend, who had become interested in the topic. I could already appreciate that there was evidence that the brain didn't function cognitively in an exact and accurate fashion, like the computers that were emerging at the same time. This could be demonstrated by considering the letter 'a'. When I am taught to read the letter 'a', I may be given a number of examples such as; a, **a,** *a,* $\mathcal{a}$,

 until eventually I might become good at recognising these various 'a's. But if we function entirely mechanistically, then no amount of teaching can prepare you for an 'a' that has never seen before, such as;  and yet it is immediately recognised as an 'a.' Fuzzy logic at least seemed to provide a description of this problem but not a solution in recognising inaccuracies around the edges of function that was useful when it came to pattern recognition. The brain would seem to have a degree of fuzziness in it's function to be able to do this and seemed to be escaping from the idea that it worked mechanistically as a large computer

Even if brain function could be reduced to the equivalent of a large computer, it would encounter another problem that software writers were beginning to appreciate. Large software programmes would inevitably contain a small proportion of machine code or software error. Finding and correcting these errors would have another chance, albeit small, of creating another error. There would come a point when the programme was so large that the error rate in correcting errors would be equal to one another. In other words, very large programmes could never be error free, something that programmers today have come to realise. This was anticipated by a corollary of Godel's Incompleteness Theorem, formulated in the 1930's asserting that 'no consistent system can formally prove it's own consistency.' When this idea is applied to software programmes, it seemed to anticipate the problem of producing error free large software programmes and when applied to brain function suggested that we could never demonstrate that we functioned in an error free manner. Even if we did function in an entirely consistent, positivist, mechanistic, error free manner, we would never be in position to demonstrate it.

Despite these occasional nagging doubts, at that time I did not seriously question the positivist basis for medicine. The way that medical knowledge organises itself also reflects the way that medical departments organise themselves. The subjects of biochemistry and physiology emphasise the idea that we are constructed of discrete, although interrelated, mechanisms. These physiological and biochemical systems dismantle human function into cardiovascular, respiratory, gastro-intestinal and many more elements. This process of

gradually dismantling the human form continues through to postgraduate medical education so that in my current position as a consultant in ear, nose and throat surgery I have come to specialise in the middle ear. This is a part of the body measuring hardly more than one centimetre by one centimetre. If my whole medical world is now centred upon a single such component in the body, the middle ear, it is hardly surprising that it is hard to shake off the idea that the whole of the rest of the body is made up of other 'building blocks'. It is, if you like, the logical extension of dismantling the body in a way that starts at medical school with anatomy and ends up with becoming a specialist ear surgeon.
For those whose interest in medicine takes them towards the holistic end of the spectrum, for example family medicine, this super-specialisation frequently comes in for criticism,

"But when a technical expert concentrates his attention on a single aspect of life, there is a fundamental difference. He doesn't have the unseen background containing everything else. Other things are 'not his field' and he simply doesn't know about them at all. Exclusion is inherent in his specialism."
(Willis J, 1995. p23)

If I do wish to practice holistic, context based medicine how are those factors that characterise a holistic approach to treatment going to be meaningfully considered by someone with a specialist knowledge of such a small region of the body? This problem suggests a number of competing variables. These include the degree of specialisation one is prepared to adopt, the attention one may wish to give to context and the extent to which one adheres to positivism. These may well be reflected in the branch of medicine one chooses to follow.

Making choices; careers and consultation styles

One of the attractions of medicine as a career is that within the broad field of medicine are a wide variety of different kinds of job. All these specialties vary enormously in the degree of commitment needed, patient contact experienced, sensitivity to non-medical processes,

manual dexterity required and in many other ways. Some are perceived as more important than others but possibly the most important is the degree of patient contact the trainee wishes to have. It can vary from none at all, as in pathology, to the considerable contact experienced in general practice. The pathologist in his or her laboratory can practice positivist medicine for much of the time because it is hard to imagine that the importance of context that characterise general practice will impinge on the pathologist's day to day task. The tumour on the pathologist's microscope slide does not have to be placed in the context of the patient's lifestyle, only in the context of the organ from which it was taken. By contrast, the general practitioner will have to constantly place the disease or problem in context. It seems likely that general practitioners will have much more difficulty than the pathologist adhering to the requirements of practising positivist medicine. These simple hierarchies are portrayed in general terms below.

Paradigm	Medical Ontology	Specialty	Space
	Context free medicine		**Small room in a**
Scientific		Pathology	**hospital**
		Biochemistry	
		Radiology	
		Haematology	
		Surgery	
		Medicine	
		Neurologist	
		Psychiatry	
		Paediatrics	
		General practice	
		Hospice care	
Holistic		Counselling	
	Context orientated medicine		**Community**

The biochemist does not have to confront the need to place their knowledge in the context of everyday life in the same way that the neurologist will. The counsellor will have less need to pay regards to the requirements of positivist based medicine. The difficulties associated with practising scientific medicine in context, can be more easily disguised at each ends of this spectrum. However, the problem is made more apparent when one

chooses, as I have done, to take up a more technical, science based specialty such as surgery and try and develop a practice that is more holistically orientated. I am asking myself to place what I do much more in context, in the context of the patient's life and at the same time pay attention to the positivist aspect of my practice.

This difficulty is highlighted in a study in which experts in tumour treatment were all asked to consider a number of treatment options. The question of context played an important role in determining treatment outcomes and this was reflected in the variability of response seen in the clinicians, who took part. By the use of questionnaires, 40 clinicians with experience of treating tumours were asked to produce their views on treatment in three hypothetical situations.

" A 42 year old barrister, who drinks a bottle of wine a day and who is married to a physician presents with a poorly differentiated (cellularly aggressive) carcinoma of the floor of the mouth measuring 4cms in diameter. Glands on both sides of the neck contain tumour that has spread from the original site. There is no distant spread (e.g. lungs) but there is local pain at the site of the tumour."
(Maher EJ, 1990, 356-9)

If 40 clinicians suggests treatment protocols for three different clinical cases, 120 different protocols are possible. In this study, 119 different treatment schedules were put forward, suggesting very little overlap between clinicians views of correct treatment. At first glance the case above would seem like a reasonable description of a problem to invite a treatment protocol but why have certain pieces of information been included? Why barrister and why married to a physician? What difference should it make to the clinical treatment options if the patient is a barrister or even married to a physician? The implication, as I see it, is that this scenario will encourage the surgeon to think *carefully* about the options, come up with the most *favourable* treatment protocol and be prepared to *logically* argue such a position with a healthcare professional and a legal mind. But shouldn't doctors be doing this all the time ? Of course they should but I suspect that they don't and so the

question implicitly, or even explicitly, acknowledges the existence of prejudice of at least one sort in thinking about treatments options. It was hardly surprising that there were so many different treatment protocols suggested because it comes as no surprise to learn that we are all going to react in different ways to this kind of qualitative input.

Furthermore the idea that a treatment plan can be adopted without a significant input from the patient was never raised in the study. This is odd because the treatment of such a condition is based around two broad options with key implications for the patient's lifestyle. The first option is major surgery, a treatment plan that is painful for the patient, potentially disfiguring with only a small chance of cure The second option is to accept that the disease is terminal and opt for a palliative approach. This is a dilemma in treatment that occurs quite frequently and one, which we encounter in a patient later in this thesis (Appendix 1). Clearly such decisions are value laden that can only be made by the patient themselves and yet in such a study there was no opportunity to obtain this input from the patient.

In the discussion section of the paper it was suggested that "...case histories were abbreviated and real patients giving their own histories might have led respondents to different plans of management". (Maher EJ, 1990, 356-9) The suggestion is that this may be an inappropriate factor to consider in a research setting. What emerged in the study was that treatment plans were heavily influenced by previous personal experience on the part of the physician accounting perhaps for the wide variety of answers given. One can also obviously propose that previous experience on the part of the patient could also lead to a wide variety of treatment options and in my opinion they frequently do, even for the most apparently simple of problems.

The same study reappeared in a supplementary paper based on the same questionnaire but published in a 'softer' medical journal. In this report it was noted that there was a "difference as to which symptoms were perceived to be the most troublesome, and therefore in need of palliation." and "overestimating the more objective "treatable"

symptoms and underestimating more subjective problems of anorexia and fear of growing cancer, when patients and doctors were compared".
(Maher EJ, 1990, 185-9)

It isn't necessary to have a complex medical problem such as the above to encounter these issues because, even before I embarked on this research project, I was finding that they could emerge in apparently the simplest of clinical problems. For example, the medical literature at the time would advocate tonsillectomy only for those patients who were experiencing more than four attacks of tonsillitis per year for more than three years (Paradise J.L. et al. 1978. p409-413). Yet there seem to be patients who did not strictly fulfil this criteria who might be expected to benefit from such an operation. By contrast there were patients who more than fulfilled the criteria for tonsillectomy and yet who were far from sure that this was the right treatment for them. It is possible to argue that most patients who were visiting outpatients had already made the decision to proceed with a tonsillectomy. If this was assumed and, as the surgeon, I described the operation, discussed operative risk, and recommended or not a tonsillectomy, the consultation would be over in a few minutes. I noticed that trainee staff, when they joined the department and started to see patients in the clinic, would frequently select such patients from the pile of notes because they did seem so straightforward. However, I found that if I were to adopt a less concrete position at the beginning of the consultation and introduced the idea of a more flexible approach e.g.

"*I would like you to know that I do not see it as my role to tell you that you need a tonsillectomy. That is a decision only you can make. I am here to provide you with more information to help you make that decision.* "

this approach would frequently unearth unexpected problems, benefits, anxieties that would I am sure, have remained unexpressed and hence unevaluated. Deciding what to do could suddenly become far from straight forward. So simply being familiar with the literature on the subject was insufficient. By creating an opportunity for patients to express

a significant input into the decision making process, I found that I was frequently unable to implement what I thought was the intellectually appropriate answer because 'it felt wrong'. The 'intuitive recognition' that it was the right treatment choice was absent even while the 'intellectual' basis for a good decision was there.

This started to generate a problem. My whole medical education had encouraged me to pay attention to the rational, analytical, positivist based approach to treatment and here I was finding that it was sometimes necessary to arbitrarily abandon it. Instead of using my scientific education as a yardstick for making decisions, I was resorting to what 'felt right'. Nothing to date had taught me that the use of intuition in this way was appropriate, so how was I to judge the appropriateness of such an action? More importantly, how was I going to equate practising in this way with new data that I would acquire from reading the journals? How was the intellectual, rational 'science of discovery' going to relate to the feeling 'science of implementation'?

I had two choices. On the one hand I could continue to practice medicine in this way, vaguely and rather randomly paying attention to either the literature or my intuition depending upon how I felt on that particular day. I could trust that my 'experience' would permit some kind of order to emerge or at the very least no serious mistake to be made. Alternatively I could continue by examining more systematically the relationship between intuition and evidence based practice and, as this thesis indicates, in 1990 I chose to explore the latter option.

Before I could even begin to consider qualitative research, I felt a need to break free from the idea that the only kind of knowledge that mattered when making a decision was positivist knowledge. Today as I write this, I wonder why I ever thought there should be any difficulty at all in accepting this but to someone educated to be 'objective', such a leap was difficult to make. It needed a moment of insight, a 'jolt' and this came with a condition, a medical condition, called Capgras' syndrome.

Intuitive Knowledge as 'science'

One day whilst considering the problem of what to do when 'intuitive recognition' and 'intellectual recognition' seemed to be at odds with one another, I read about Capgras's syndrome. Reading about this syndrome became a bridge that spanned the 'old' and the 'new' ways of thinking. Because it was a medical syndrome it contained a language and logic that I could understand and so provided just that sufficient impetus to encourage me to reconsider where I stood on the question of what was meant by 'knowledge'.

Capgras's syndrome was first described in 1923. In his first case, he described a 53 year old woman, who complained that her family was being replaced by identical doubles. Later she began to experience the same feeling about friends and neighbours and felt that she existed in a world of impersonators. About 300 other cases have since been identified including one, in which a son was so convinced that his father had been replaced by a robot that he cut open his throat to try to find the wires. At first it was thought that such individuals suffered from a form of paranoia but it is now thought that such individuals suffer from a failure of 'intuitive recognition'. Identification of objects, people, ideas, not only involves an 'intellectual recognition' but an 'intuitive recognition' or a sense of 'aha!'. The 'aha' feeling in these individuals is absent. Capgras's syndrome seems to arise from damage to a 'sense of familiarity' pathway in the brain and modern brain imaging is beginning to understand this more accurately. The reverse possibility of having 'intuitive recognition' but not 'intellectual recognition' also exists and is called Prosopagnosia. We occasionally obtain insights into this phenomenon when we experience deja vu.

What is the significance to me of this rare syndrome? Whilst reading about this I could see that I had been working and thinking in a world to which I only gave credence to 'intellectual' recognition and understanding of phenomena. The medical world lends weight particularly to double blind, randomised, controlled trials and regards them as the only acceptable way of unravelling and understanding phenomena and disease to provide insights into what would be an appropriate treatment. For example, decisions to treat by

surgery, radiotherapy or chemotherapy were to be based on the results of controlled randomised trials. No credence at all is given to the so called 'aha!' feeling, in fact this is regarded as an unscientific prejudice and all studies will endeavour to remove any such 'intuitive prejudice'. Capgras' syndrome described what happened when the intuitive recognition pathway was damaged. I started to appreciate that when viewing any object, for example a tree, that not only was I processing light from the tree as it landed on my retina to produce an image that was a tree but before I could say to myself that "ah! haa! it is a tree.", an additional process of 'intuitive recognition' was needed.

My own belief system that I called 'science' was called into question by this insight. As I had been taught, from school, to university and thereafter I had been encouraged to think and act in a certain positivist way so that eventually I would only give 'intuitive recognition' to a certain kind of science. I might notice findings that didn't fit in with this positivist view of science, even be interested in them, perhaps comment upon them, but I had learnt not to give them this 'intuitive recognition' of science and thus learnt to ignore them. Any finding that wasn't positivist in construction would not be given that 'ah! haa!' feeling and that this response was a *learned, conditioned* response. I was beginning to realise that I had become too narrow in my definition of what constituted 'knowledge'. It was necessary to begin to break away from this narrow circumscribed definition of what constituted knowledge.

In a sense then, my approach to the question of knowledge, what constituted relevant knowledge had come full circle and I see this in relation to the changes I see in one of my children. I started this thesis shortly after my second child Laurence was born and I cannot help but draw parallels between his development from baby to infant to boy and the development of my own PhD from germ of an idea to more organised thoughts. Both have taken about five years. But in one important way both he and I have gone in opposite directions. He has developed his ideas about the world by changing his experiences, thoughts and ideas from an apparently random collection of encounters to one of an organised world with meaning. I have taken to some extent the opposite path by taking my

organised world, with for example specific definitions of what constituted knowledge, and expanded these into a somewhat disorganised world of knowledge. As he learnt to make inference from data, I was appraising data and the inference derived from it. As he was being *conditioned*, I was recognising the degree to which I had been *conditioned*. In order to make progress on this issue, it was going to be necessary to re-evaluate what constituted medical knowledge. How was this going to be done?

This process starts by asking a number of basic questions. Why has medical education concentrated on the development of a scientific approach? If this is a deliberate strategy then what is the purpose behind this strategy? If there is a purpose behind teaching this kind of medical approach to students, then what is the purpose underlying the practise of medicine itself and are they linked? Is it possible to start thinking whether medicine fulfils some other purpose other than the apparent one of healing? If this is so, then will an understanding of this purpose become important when considering the whole subject of decision making?

This approach enters a world where knowledge may be institutionally determined by traditional, cultural and historical practices, where intention and purpose may serve to influence what is accepted as knowledge and what is not. This meant beginning to see relevant clinical data as a particular interpretation circumscribed by a set of assumptions. This called for an approach that explored these assumptions and the historical and cultural influences that underpinned them.

MEDICAL KNOWLEDGE

Medicine, surgery, science, ceremony, ritual, sacrifice and magic.

Introduction

This is perhaps a curious and provocative subtitle for a section that is purporting to try and answer some of the questions posed at end of the previous section. What have ceremony, ritual, sacrifice and magic got to do with teaching medical students or the underlying purpose of medicine? The last section suggested that medical training shapes a particular positivist viewpoint, to the exclusion perhaps of other viewpoints in the medical student and doctor. This culminates in the belief that the only 'medical knowledge' that matters is knowledge based upon a structure of anatomy, physiology and biochemistry. I am suggesting that this epistemology may be too exclusive to be always useful in the practice of everyday medicine. This section represents an exploration into purpose behind medical practice. Such purpose might include the need for ritual, ceremony, magic, sacrifice, spiritual engagement or whatever. By paying attention to the possibility that other needs may play a part in the process, the concept of relevant 'medical knowledge' may be widened. What follows in this section is an attempt to broaden the notion of what is happening in a clinical encounter beyond the apparent one of a medical interaction where a doctor simply treats a patient. To do this I have attempted to once again look at everyday events in the hospital with a phenomenological perspective.

At the heart of phenomenology is a reflection on essence (universal properties) and their connections. This reflection requires 'eidetic reduction' and "by means of eidetic reduction, we shift our attention from a particular instance of a property to the abstract property (essence) itself" (Grossman R.G. 1995 p658-660) This approach was an invitation to look for some indirect knowledge underlying the direct experience of the practice of medicine. In other words, what is the practice of medicine *really* about?

Phenomenology begins with a general prescription to look at things again without prejudice, to try and loosen any paradigmatic assumptions that have so far limited interpretations. Such reflections try to get at the 'essences' and their connections with different cultures, with different ceremonies, and with other historical practices. In adopting this approach, I have attempted no special study of the relationship between such 'essences' I felt might be present, for example common to surgery and sacrifice, although I did consider doing this at one time. The reason for not pursuing this approach was that such knowledge was almost certain to be non-empirical and such a journey would almost certainly have completely divorced me from my colleagues. These thoughts then represent some early ideas in a narrative account that served to jolt me out of a world bounded by a more conventional, medical interpretation of what was happening and should be viewed as such.

The first section **Tonsillectomy, Inca sacrifice, witchcraft and maintaining belief systems** takes an everyday operation, tonsillectomy, and looks at how the indications for this operation have changed over the years. As one indication becomes discredited, another emerges and I suggest that there may be reasons for this that connect what we do with the activities of other belief systems. This leads one to suggest that part of the underlying purpose behind medicine may be fulfilling a need for ritual, magic or sacrifice. This idea is extended to other areas of hospital activity in **Outpatients as a visit to a temple**. In **Anatomy lesson** I hypothesise that these underlying purposes are implicitly understood by the medical world and are introduced during training. I put forward the suggestion that the *way* medical students have been taught not only fragments a holistic view of human function but prepares them for the implicit role as a modern day priest. This might partly explain the way that doctors view themselves and the way that doctors are viewed by others. In **Validating these Observations** I try to raise some arguments to substantiate these conjectures. In reading this it should be remembered that this whole section charts an attempt to completely re-examine the professional world I inhabit.

Tonsillectomy, Inca sacrifice, Witchcraft and maintaining belief systems

Some time ago (1991) I was engaged in some traditional mainstream medical research. The study examined sleeping disorders in children. There are a group of children, usually between the ages of three to six or seven years old, who have tonsils and adenoids that are so large that they cause problems. During rapid eye movement sleep and when muscle tone in the muscles of the pharynx diminishes, they will experience obstruction of their breathing. The oxygen levels in the blood will fall and they will gradually become aroused from sleep. Eventually they will wake up, regain pharyngeal muscle tone, open up the airway, start to breathe again and oxygen levels will return to normal. If this pattern is reproduced time and again during the night, there was evidence that severely effected individuals experienced heart and lung disorders of an irreversible nature. This is known as the sleep apnoea syndrome. Severely effected individuals are rare but it is much more common to see children who are more modestly affected by sleep apnoea. It was assumed that in these individuals the condition was also harmful. An understanding of this problem meant statistically analysing the results of overnight oxygen measurements, urinary growth hormone levels and a host of other parameters. But the question I started to ask was; Why had it taken until the late twentieth century to recognise this condition?

Tonsillectomy is a traditional operation of ear, nose and throat surgeons and has formed a substantial part of their day to day practice. What I noticed was that as recurrent tonsillitis, the traditional rationale for tonsillectomy, was falling slightly out of favour, a new more 'scientific' re-interpretation was emerging to maintain it's place in medical practice. Kuhn has maintained that scientific thinkers may be prepared to consider alternatives but continue to have a protective attitude towards established theory. He called this protective attitude secondary elaboration and one function of this is to maintain a belief system. (Kuhn, 1972. p78). Was this an example of secondary elaboration to maintain a belief system? An examination of the operation in it's historical context might help decide if this was the case.

Tonsillectomies and partial tonsillectomies have been performed for at least three millennia. Ancient Hindus about 1000 BC advocated removal of one third of the tonsil. Celsus in 50 AD, Galen (AD 121-201), Aetius of Amida (AD 490) and Paulus Aegineta (AD 625-690) all describe the operation and suggested developments in the technique to remove the tonsil. Guillotine tonsillectomy was described in 1828 by Physick and the contemporary method of removal by dissection was described in 1897 by Ballinger. Reasons why tonsils were removed in ancient times are unknown but in recent times, in the last two hundred years, the main indication has been for recurrent tonsillitis but tonsillectomy has been advocated for a wide variety of other conditions. These include frequent head colds, recurrent ear infections, glands in the neck, recurrent fever, recurrent hoarseness, frequent nosebleeds, frequent headaches, restlessness, rheumatic fever, growing pains, rheumatic carditis, loss of appetite, failure to thrive, mental retardation and bed wetting at night. (Barrington-Ward, 1922. p1101-6; Paterson & Bray, 1928, 1074-5; Bartlett, 1928. p26-35; Kaiser, 1930. p837-42; Guymer, 1934. p85-113; Clein, 1952. p568-73; Paradise, 1983. p992-1006). Furthermore, chronic infection in childhood could lead later in life to "psychosis, gastric and duodenal ulceration, pernicious anaemia, urinary stones, acne, optic neuritis and Meniere's disease". This association was based on the idea that chronic infection in one part of the body could, by transmission of the micro-organisms or toxins, lead to problems in another (Billings, 1916.). Nevertheless, despite these curious and constantly shifting indications for removal of tonsils the operation continued to be very frequently performed. In 1931 a study observed that one third of school leavers in London had had their tonsils removed and in the twenty years between 1920 and 1940 the tonsillectomy rate was about 50% (Collins & Sydenstricker, 1927). This could vary between 1.6% to 61% depending upon the area from which the children came, or depending upon the examining doctor. In highly selected privileged groups, it may even be higher. In 1938 it was reported that on average 75% of boys entering Eton public school had undergone tonsillectomy prior to admission. There were also great variations in incidence of tonsillectomy from one country to another. During the same pre-war period, tonsillectomy was much less common in Germany for only 0.5% of secondary children in Munich had undergone a tonsillectomy (Glover, 1938. p1219-36). This brief

review should make it clear that although there has always been a great variation in the incidence of tonsillectomy depending upon social background, doctor, current medical belief systems, country etc. the operation has been performed for three thousand years in many different countries.

Most of the reasons for tonsillectomy promulgated in the past seem ludicrous to us today but what seems to have happened is that as 'progress' took place, the reasons for tonsillectomy would alter and indications for tonsillectomy appropriate for the scientific viewpoint of the day would displace 'outdated' notions. This obviously led me to consider whether or not my own work on tonsillectomy was yet another 'secondary elaboration to maintain a belief system'. Did the strategy to justify tonsillectomy alter whilst the purpose, the *real* purpose, remain unaltered?

It was already clear that there was a certain sustainability about tonsillectomy as a procedure that seemed to go beyond it's apparent function in the surgical portfolio. As an operation "it wouldn't die easily." Was a threat to the need for such an operation challenging a belief system that went beyond the bounds of rational science? Was challenging this ancient operation as a surgical procedure challenging not only the operation but surgery in general? Was *surgery itself* an elaboration to maintain a belief system? If so what was the underlying belief system that was being challenged by challenging the role of surgery in this way? Was the ritual itself part of a belief system? Nadel and Firth have both attempted to define the notion of ritual and it would seem to me that surgery, or at least some surgery, may be fulfilling these requirements.

"When we speak of 'ritual' we have in mind first of all actions exhibiting striking or incongruous rigidity, that is, some conspicuous regularity not accounted for by the professed aims of the actions. Any type of behaviour may thus be said to turn into a 'ritual' when it is stylised or formalised, and made repetitive in that form. When we call a ritual 'religious' we further attribute to the action a particular manner of relating means to ends which we know to be inadequate by empirical standards, and which we commonly

call irrational, mystical or supernatural"(Nadel, 1954.) Firth saw ritual as "as a rite or verbal formula projecting man's desires into the external world on a theory of human control, to some practical end, but as far as we can see based on false premises." (Firth R. 1958. p124) The sustainability of the operation of tonsillectomy leads me to consider whether the operation has a strong ritualistic, spiritual or magical component to it.

My search for some underlying purpose has resulted in a profusion of words here; ritual, spiritual, magical, all of which may be to some extent interconnected. It might be appropriate to start with perhaps the least contentious notion and look for the role of ritual in surgery. Is a surgical operation a *rite* according to the definition of such a procedure as "a rite or verbal formula projecting man's desires into the external world on a theory of human control, to some practical end, but as far as we can see based on false premises." (Firth 1958. p124)

Surgery as a ritual would seem to be a relatively straightforward point to begin. Some operations with religious connection are clearly ritualistic. A circumcision in Western countries and clitorectomy performed as part of an Islamic adolescent coming of age are clear cut examples of rituals. But there are operations where the sense of ritual may be less obvious but may be signifying transitions in life. Vasectomy in men and hysterectomy in women may be denoting the passing of the procreative phase in life. Other operations might also denote transition points in life; prostatectomy (ejaculation generally ceases after the traditional prostatectomy) suggests the cessation of biological sexual function; gall bladder removal and coronary artery bypass grafts are statements about transitions from a lifestyle that produces diseases of excess intake. Sometimes, at the end of life there is the ritualistic surgical attempt to stave off death by malignant disease or coronary artery bypass surgery; transitionary surgery from life into death. Could tonsillectomy be part of the transition into adolescence? I am not suggesting that the need for ritual constitutes the sole reason for surgery, but I am suggesting there is something here about passage and rites of passage.

For myself, I have little difficulty in appreciating the ritualistic element in surgery but I would like to take this hypothesis a little further and suggest hidden within all this there is something else happening. For want of a better word I call this sacrifice. Put another way, I am asking whether there are 'essences' in contemporary medical practice that can be related to a more traditional notion of sacrifice? Here I am on *really* tricky ground because there is no real evidence as such for speculations of this sort, other than observing and experiencing hospital life both as a patient and as a doctor.

I have just read a most moving account of the discovery of the remains of a young girl, probably no more than eight years old, who was found 19,000 feet up Nevado Ampato in the Peruvian Peaks. She was found resting in a tomb, surrounded by valuable objects, and was thought to be part of a sacrifice to the Inca Gods nearly five hundred years ago.

"In the morning, she may have taken a drink of chicha; if so, the alcohol would have clouded her mind.....We can only suppose what the girl's last moments were like. Although she must have been frightened, she may have felt honoured to be selected as a sacrifice, imagining that she was entering a glorious afterlife with the gods in a palace within the mountain."
(Reinhard, 1996. p79)

In the article, there are accompanying pictures of her small pairs of shoes and other artefacts associated with a small girl. She might not have entered the palace she was hoping for but she elicited a most moving response in a twentieth century surgeon as he types away at his word processor five hundred years later and no doubt many others who also read the article. I have no way of knowing whether the priests carried this little girl up the mountain would know that eventually this act would re-emerge as an experience for others many years later, but the power of such an event, the influence of sacrifice of this sort is clear to me. Although I would have previously regarded such action by the Inca priests as quite divorced from my function as a twentieth century surgeon, given the

aforementioned frame of mind, I find myself asking whether my actions as a surgeon is in any way equivalent to the behaviour of those Inca priests five hundred years ago?

I began to consider for a moment the operation of adeno-tonsillectomy frequently performed on young children and asked myself; Is there anything about this activity that could be equated with the notion of sacrifice? As I see it, the answer is that there may be. Such surgery carries with it a small risk of death, is a seasonal operation so is more common in the winter (possibilities here of seasonal sacrifice for a good summer harvest), more likely to be undertaken on social class three, four and five (less powerful ? dispensable members of the community), children (sacrificing to the Gods my best/most precious animal/possession), young children (pure and unsullied), fasted and given a premedication (something to cloud the mind), anaesthetised (made senseless by magic concoctions), undertaken by surgeons (high priests/druids etc.), who have spent years training (initiation rituals), in operating gowns (ceremonial dress), surrounded by nurses (virgins), in hospitals (temples). It can be seen that this is a heady concoction of archetypal themes that can at least echo the activities of the Inca community or any other community that we might regard as 'primitive'. I accept that each of these associations with contemporary practice may well be justified on scientific grounds but I could also argue that they may be little more than secondary elaboration to justify a more fundamental archetypal need; perhaps the need for sacrifice of some sort.

But why, one is led to ask, do we need sacrifice? It has been suggested that the need for such sacrificial ritual might be 'to ritualise man's optimism' in the face of problems. (Malinowski, 1925. p90). This may, or may not, be true but there is no doubt that maintaining such a need for sacrifice in this manner carries with it certain risks. If that is so, then what is the attitude of the general population to this risk? For if society accepts such risks, this may say something about perceived need or benefit.

One constantly needs reminding that surgery is a procedure with substantial risk. Nevertheless, I have always found it difficult to appreciate why society seems to accept

that death will sometimes happen at all. For example, the risk of death from tonsillectomy is usually considered to be in the region of 1:15,000 but to me this risk seems enormously high. As a surgeon, who undertakes many tonsillectomies, I take the view that a single death during a tonsillectomy would negate all the benefit from 15,000 successful tonsillectomies. Curiously though, society seems to accept this level of risk for in one study "over 90% of the parents felt that they understood the risks of anaesthesia, that the discussion of the risks would have no effect on their decision to proceed with surgery." (Waisel D. 1995. p200)

The surgical literature seems to accept that an occasional death is an acceptable price to be paid for successful surgery because each year in this country three or four children will die whilst undergoing a tonsillectomy. Put like this, I start to wonder what it is that makes the attitude and practice of earlier societies such as the Inca society 500 years ago dissimilar from ours to today. Suddenly within the midst of a scientific subject, I find, "the rebirth of ancient topics of craft, artistry and myth-topics whose fate positivism once claimed to have sealed." (Schon. DA. 1983. p48). Suddenly "treatment can be viewed partly as a magical system." (Posner, 1984. p50).

If for a moment it can be accepted by the reader that there is at least a small number of surgical procedures that have a ritualistic, ceremonial or sacrificial component, what further evidence can be gathered from more mundane practices within a hospital? Where is the ceremony, ritual and magic in, for example, a simple visit to outpatients?

Outpatients as a visit to a temple.

In more recent times, as early as 4000 BC religions clearly identified certain of their deities with healing. The temples of Saturn, and later of Asclepius in Asia Minor, were recognised as healing centres. Brahmic hospitals were founded in 431 BC in Sri Lanka and in 230 BC in Hindustan. The modern concept of the hospital dates from AD 331, when Constantine

following his conversion to Christianity, abolished all pagan hospitals. The Christian tradition of medicine emphasised the close relationship of the sufferer to his fellow man and thus illness came to be a matter for the Christian church. Later on, in the middle ages, throughout Europe and the Arabic world, great hospitals were established by religious foundations, and infirmaries were attached to abbeys, monasteries, priors and convents. "Doctors and nurses in these institutions were members of religious organisations and combined spiritual with religious healing." (Encyclopaedia Brittanica. 1991, p890).

Many hospitals today bear testimony to their historical origins with names like St Thomas's, St Martins, St George's, Mount Sinai etc and it leads one to consider whether there is then a connection between the decline in the number of churches and church attendance and growth in the number of hospitals and hospital attendance. As churches, dedicated to the celebration of death and built to celebrate what we cannot see, decline in numbers, hospitals, dedicated to the celebration of life and built to celebrate what we can see, increase in numbers. Both celebrate in a sense the same thing; life or it's antithesis death. Hospitals might indeed be considered then as a secondary elaboration from churches and built to maintain a belief system surrounding what happens at the moment of death.

This relationship, between the structure and the activity undertaken within the structure, has been called the 'edifice complex'. It occurs when the "patients invest the hospital itself with a healing function, and assume that whatever goes on within it's walls is done to help them." (Frank J. 1978) In psychoanalytic terms it is transference to the institution.

Viewed with this new perspective in mind, a visit to outpatients may be seen in a different way as a temple, as a church or as a place of 'worship'. Just like priests, senior doctors and surgeons are usually men. They are located in temples, known as hospitals, the importance of which, like temples, is based on size. It has been observed that "western therapists commonly utilise the edifice complex to raise client expectations, although they are not usually aware of using it." (Torrey E. p60, 1986) Patients will usually be prepared

to travel to hospital and sometimes this 'pilgrimage' will be a considerable distance and at some personal cost. I have known patients travel from Bath to London to see someone for less than five minutes and some may well have given up a half a days work, and hence pay, in order to make this visit. Upon arriving the patient is met by a courtier/acolyte, better known as a receptionist, who with others (nurses) control access to the surgeon. These other courtiers are often women who have given up their lives to serve within this organisation, many of them are unmarried and wear uniforms and hats that bear a striking resemblance to those of religious institutions such as nunneries. There is a crowded waiting room full of people waiting for an audience; the more people who wait and the longer they wait the more this seems to reflect on the importance of the surgeon.

When the patient enters the consultation room, the furniture is unfamiliar, with a number of ceremonial implements on display such as shiny medical instruments. There is a large chair for the doctor, small one for the patient, separated by a large desk. The 'pilgrim' might be asked to take off their clothes, which is then replaced by a long white gown looking for all the world just like a pilgrim's gown. Sometimes this is done before the 'pilgrim' even enters the room denying such a patient any opportunity to project themselves as an individual. The room is often slightly darkened to make it easier to use lights, which are used to shine into orifices e.g. mouth, ear, anus, vagina. In my specialty the light is worn on the head like a crown and almost invariably this bright light is shone into the eyes and face of the patient as part of the examination. It is interesting to note that in cartoons and doctors are often represented by gowned individuals wearing a headlight/mirror. In actual practice very few doctors actually use this device. Why should this be the case unless it is indicating something else as well as portraying a doctor? The picture one conjures up is that of facing someone, who is higher than you, in a larger chair, who is shining a bright light into the face which makes it impossible to look directly at them.

A detailed history or 'confession' is then taken. Sometimes the patient will be sent down to the x-ray department, a smaller 'side temple' with a 'magical' device, and may return

with an x-ray film. Here one can begin to really connect with other medical cultures, with superstition and magic. The doctor now takes the x-ray from the packet and 'reads the bones'. A visitor from outer space might see no qualitative difference between this activity and a visit to a native doctor in central Africa, who would also take a history and after throwing gorilla knuckles onto the ground, 'read the bones'. (conversation with medical friend). As some have observed it is part of the unconscious medical imperialism that we show towards other systems of medicine that "we implicitly and automatically assume that therapy that goes on in an office in a modern skyscraper or in a complex medical centre must be scientific, whereas therapy that goes on in a grass hut must be magical. If one is magic then so is the other." (Torrey E. p 11-12, 1986)

In fact we embrace superstition and magic in our everyday lives; we are superstitious about the number 13; ten million rabbits foots are sold every year in the United States of America; we knock on wood; we walk around ladders; read the astrologers predictions of the future; we turn bread and water into body and blood and all are reminders of our contact with the world of magic. It would be surprising if we did not expect to find it at all in the healthcare system and as Torrey has suggested "it may be that we don't want to see this magic in our lives, so we just see it in witchdoctors and call what we do as 'science'." (Torrey E. p13, 1986)

I find myself beginning to consider that much of everyday western medical practice has it's counterpart in the medical practice of other cultures in the world and to be rooted in historical traditions of worship and healing. To see the connection it is necessary to look beyond the technology and look at the activity at the level of intent, belief structure and archetypal theme, not at the level of syringes, scalpels and x-ray machines. Much as we would like to concentrate on the considerable progress in treatment that has been made in the last two hundred years, at the deeper level I am left wondering if little has changed since the dawn of modern man, a mere 40,000 years ago.

In trying to present the argument that under some of the activity of the medical profession

lies a deeper need for ceremony, ritual, need for magic and sacrifice, I admit to having chosen to highlight those examples where I think that this is more evident. It does not mean that I deny the importance of medicine of relieving pain, treating the injured, comforting the sick etc. but admit the possibility that other things may be happening as well. I would see some hospital episodes as having a significant ceremonial, ritualistic and sacrificial components, e.g. a circumcision, and I would see other episodes as having virtually no ceremonial, ritualistic or sacrificial component, e.g. treatment of tuberculosis. It suggests that an awareness of these other needs may play a part in understanding why decisions for surgery may be made.

Anatomy Lesson

My arguments so far are suggesting a more complex role played by the actors than simply engaging in healing. If that is the case, then is there 'evidence' that this is reflected in the way that medical students are prepared to take on this role? In discussing how the medical student is prepared for their role of 'modern day priest', I have chosen to emphasise the subject of anatomy. The reason for doing this is historical and personal. It is historical because the subject of anatomy has played an important role in the systematisation of medical thought. It is personal because my own response to taking part in dissection first made me conscious that something more than anatomy was taking place.

Introduction of anatomical dissection was, of course, part of a much wider change in the approach of science and scientific thought. The prepositivist Aristotelian attitude of 'passive observer' had lasted for nearly two millennia and was becoming transformed by the 'active observer' positivist science of Newton and those who followed. (Lincoln & Guba, 1985. p18-9). This was reflected in medicine and medical education by 'active' dissection of human and animal cadavers. So it could be argued that the introduction of anatomy dissection in the late middle ages was the first step in the process that changed the way the human body was regarded by the medical profession and began the

mechanistic approach that characterises modern medicine. This analysis of human form into discrete and separate components has come to be reflected organisationally, after two or three centuries, in the way the medicine is practised at hospital level. Each specialty concentrates on certain anatomical areas of the body; respiratory physicians, neurosurgeons, renal physicians, urologists, ear nose and throat surgeons all have an interest defined by anatomical boundaries. Medical practice could have been classified in different ways, for example according to age or sex or star sign or whatever but the way it is currently organised probably owes its origins to the study of anatomy. For the last two hundred years anatomical form has been principally responsible for the way medicine is organised. However, in addition to making the argument that the study of anatomy has been instrumental in the fragmentation of the holistic view of human health and disease, I am advocating that there is a secondary function in preparing for the role of 'high priest'. It is this secondary role that I wish to discuss in greater detail.

Making the case that the study of anatomy prepares the student for a role of 'priest' is a difficult argument to make convincingly but the first point to make it that dissection of the human body breaks a great taboo, perhaps *the* great taboo. I found that breaking this taboo was accompanied by a certain fascination, some revulsion and not a small degree of voyeurism. Historically, this taboo was first broken by dissection of less fortunate, marginalised groups so that it was part of the punishment of an executed criminal to be dissected in public. The execution was in public and so was the subsequent dissection. Rembrandts painting, *The Anatomy Lesson of Dr Tulp* was, "..of a horse thief Aris Kindt who had been executed in Amsterdam on January 31st 1632. In those days anatomies had to be in winter because otherwise the cadaver would stink. Winter was the season for anatomies in the same way there were ball and hunting seasons, with the public buying tickets to anatomies carried out in theatres just like any other entertainment. Rembrandt had gone along to make drawings of the corpse.....It is the voyeurs ultimate dream of furtive pleasure, looking with impunity through the keyhole of death." (Morley, 1995. p140) Medical faculties would be granted a licence to dissect the corpses of criminals, for

example in 1694 the Edinburgh Town Council granted ten members of the university's medical faculty the corpses of "foundlings, suicides and homicides for dissection." (Newman, 1988. p 63)

In some parts of the world this is still happening today. A colleague recently attended a conference in Singapore where surgical demonstrations were conducted on fresh corpses. When some delegates inquired how they were obtained for the course, they were informed they were executed criminals, who in return for special privileges in the last few days of life, had given permission for their bodies to be used in this way. This had made it possible for the course organisers to have a corpse that was only an hour or so old. Most delegates were deeply disturbed to learn of this fact and a number withdrew from the course. The voyeuristic aspect of watching the body being dissected has recently been highlighted by the attempted publication, halted at the last minute by legal action, of a film of common operations performed in the National Health Service (Everyday Operations. Reference unavailable). The panic about the video has been curious. As one commentator remarked

"Commentators have struggled and failed, to mark clear distinctions along the sliding scale that includes intellectually-motivated curiosity, voyeurism and exploitation..... It is rather that this reminds us of how complex the issues are surrounding the public display of the human body, its relationship to notions of public decency and its role as an effective forum for demonstration of intellectual curiosity.....But it was not so long ago that such curiosity was deemed the hallmark of the cultivated man."
(Irving M. 1996.)

What does all this publicity about dissection mean? It means that whatever happens in a medical school is very much in the eye of the general public and today, two hundred years later, many patients have an inkling of what happens when a student undergoes training. This becomes part of the "social sanction for the therapist in the broadest sense and reputation in the narrowest sense." (Torrey E. p63, 1986)

When I first took part in anatomical dissection, I was immediately struck by the ritualistic, primitive nature of what we were doing. Instead of a rite of passage involving tattooing, circumcision etc. we seemed to be engaged in a rite of passage involving anatomical dissection. It seemed an extraordinary powerful a position to be in, being able to look inside a dead body in the most intimate way imaginable. We all seemed to be conscious of breaking the great taboo of touching, handling, dismantling people. This was given greater impact by the fact that all this occurred on virtually the first day of the course. Perhaps this early experience of breaking a significant taboo helped when it came to breaking other taboos, such as asking awkward and personal questions of patients. Certainly from my point of view, being a witness to dissection left me feeling different in a way that I find difficult to describe. Curious, repelled, tainted, touched whatever but effected none the less and made more so by the curiosity extended towards you by other students who wanted to know "what it was like" and who occasionally secreted themselves into the anatomical dissection room to satisfy their own curiosity.

If this process really served a useful purpose in learning anatomy, I should be able to look back and say to myself that it may have been an unpleasant but it was invaluable as a learning opportunity and this knowledge couldn't have been acquired in any other way. What is retrospectively evident is how little of the information gained in this way was of any clinical use in everyday practice. When I embarked on a career in surgery and worked for postgraduate surgical exams, it all had to be done again. Dentists, who spend a lifetime doing little more than filling teeth, embark on a years' course studying anatomy of the head, with careful dissection of structures that they never see again, acquiring knowledge that they never use again. All this certainly makes one raise the possibility that there are other purposes for undergoing the *ceremony* of anatomical dissection.

What is the evidence for believing these observations have disturbed some in-built assumptions?

I am conscious that so far I have engaged upon considerable speculation based on personal experience. How do I justify to myself that a reappraisal of assumptions was taking place? I recognise that I do so as a kind of emotional response to these 'insights', usually humour or embarrassment, which I choose for the moment to call 'emotional validation'. What do I mean by this?

When my colleague and I had made the connection about 'reading the bones' and x-rays related earlier, we had both broken into laughter. This laughter, we agreed, had arisen out of a realisation that we had previously failed to notice this particular and real for us connection between our everyday scientific practice and something much more apparently primitive. This is quite like one form of triangulation that has been referred to as respondent validation (Cohen & Manion 1989 p278). However, I mean more than that. I have worked in hospitals for many years without even considering the question of ceremony, ritual or sacrifice, but once I began to see the organisation within which I work I experienced an emotion when I recognised components that suggested these things. For example it made me *smile* with recognition when I saw a traditional nurses hat and 'saw' a nun's wimple. It made me *embarrassed* when I realised that before I was aware of such historical influences I would, as a matter of form, fail to introduce myself to patients on a ward round. After all, patients should know who I was. In fact most doctors, especially the most recently qualified, failed to introduce themselves properly, a pattern of behaviour quite different from everyday convention. This began to suggest that feelings of humour, embarrassment, irritation, surprise could be hallmarks that suggested a process of change or a re-evaluation of assumptions was taking place. I do not take the view that such feelings represented rigorous qualities of change of viewpoint but when they occurred time and again they began in my mind to be worthy, in this situation at any rate, of being considered as responses that confirmed something was happening. Goleman issues a word of warning in this respect by commenting that emotions can be regarded as reactions in the

present for events in the past. 'Emotional thinking' of this sort tends to be self confirming (Goleman, 1995. p295). If I adopted a new stance, one that suggested that challenging previous assumptions about medical practice was a useful one, what was the process that validated it for me? How do I justify to myself the statement that 'emotional validity' exists?

I do so purely on a pragmatic basis but the pathway to this pragmatism is not straightforward. Saying that I believe that 'emotional validity' exists is a cognitive stance that includes both my belief and what I take to be my knowing. Implied within this is an attitude towards the strategies and methods necessary to acquire further beliefs and abandon old ones. So that if I am told or tell someone that 'emotional validity' exists but I, or they, do not *believe* it, the new perspective is unlikely to lead to further insights. This leads in turn to a discussion on the source of a *right* to believe. In my case it arose from a starting position that made me unwilling to adhere to my previous epistemology and was affirmed by the fact that the early process of loosening my belief in positivism and starting to examine the world through other frameworks, appeared to lead to insights that were useful. They were useful in that they permitted new inferences that 'appeared' to be justified. What made them appear to be justified? Firstly they seemed to inform in a reliable manner as evidenced by sustainability and usefulness, and secondly they seemed to provide a more coherent explanation of my working environment. Certain phenomena made more sense when previously they made none.

I don't propose to enter into a discourse about the taxonomy of justification, except to say that if things appear to be that way, then I am likely to adhere to this view until I have reason to doubt it. Of course the belief sceptic will respond by advocating that no one has a right to any of their beliefs because none are better than others. On this basis any kind of justification is impossible. This in turn leads me to be consider whether the whole process of validation is asking one to demonstrate that their beliefs align closely enough with another's to be taken seriously. If someone else perceives the world in a way that is significantly different from my own perception, then how can I expect to achieve coherent

validation in their eyes, unless I stick to 'safe' conjecture? Others have expressed the same thoughts.

"It is fallacious to conclude that the propositions of a system of thought can be proved, disproved, or evaluated on the basis of axioms within that system, since the process becomes self-justifying. This means that it is not possible to determine the validity or contributions of different research strategies in any absolute sense in terms of evaluative stances that draw on the same assumptions as do any of the research strategies examined. Unless it is possible to find an independent point of reference against which the nature and claims of different research strategies can be assessed, all evaluative efforts encounter a relativism in which it may be possible to say that one research strategy may be more effective for a specific purpose than for another....but ultimately the different research strategies do different things, and that as far as their contributions and knowledge claims are concerned we should conclude that "anything goes"
(Morgan 1983. p370)

Where is all this leading? It is to point out that this section represents the beginnings of a transition of belief from one epistemological stance to another and there has to be a moment when belief that this may be an appropriate way forward provides the impetus to continue the journey. However, if this transition is examined carefully enough, it may be impossible to extract myself from a position of self-referencing justification. Nevertheless, in empirical terms, such a loosening of assumptions enabled me to reconsider what I regard as relevant 'data'. I noticed, as I did this, that I *was*, for a moment, prepared to suspend the notion of rigorous justification as I began to shift ontology. So part of my argument today is that it may be necessary to reduce criticality by suspending belief to effect change but, and this may be difficult, to retain criticality as this shift progresses. The same criticality that monitors such a change might indeed be a hindrance in permitting such a change. It makes me consider the position of critical awareness carefully because in certain circumstances it may become an obstacle to evolution of thought.

This section represents early moments when my original assumptions about data and validity were disturbed and when I began to appreciate the need for a new set of criteria to judge validity. Continuing to adhere to positivist principles of validity was going to be inappropriate in contemplating qualitative research. Just as Capgras' syndrome provided the 'jolt' to consider alternative forms of data as knowledge, 'emotional validity' provided the jolt necessary to accept new forms of validity criteria.

This section then represent the beginnings of a search for a self inquiry system "that illuminates previously hidden core assumptions" (Torbert 1983 p273). It represents the beginning of a creativity cycle characterised by three phases of circumspection, "a phase of unbounded wild speculation and free association," pre-emption, a phase of exploration and evaluation and finally control. (Banister, Burman, et al. 1994 p144)

RESTRUCTURING THE MEANING OF 'SCIENTIFIC KNOWLEDGE'

Introduction

The previous sections have suggested that I have been educated to think of relevant, clinical 'knowledge' only within a positivist perspective and such an approach tends to marginalise qualitative based knowledge that cannot be presented within such a perspective. This meant recognising that medical knowledge was theory and value driven and this implied that the patient's own medical knowledge would be theory and value driven as well. It was an assumption to maintain that the theory and values that underpinned medical data were superior to the theory and values that underpinned patient's medical data.

This section explains how I was preparing to shift from a positivist to a constructivist ontology. Since part of my early difficulties were related to the separation of theory from practice (Argyris, Putnam, et al. 1985 p4) this meant that what I was prepared to accept as data began to change. This commenced with acknowledging the work of Heron that propositional knowing is dependent upon other forms of knowing and I offer an interpretation of this idea within the context of a medical encounter. Using an ethnographic approach, I suggest that there exists a complex network of knowledges that includes compassionate, organisational, community, traditional, cultural, technical, ceremonial, ritual, spiritual and sacrificial knowledges that pervade medical practice to a greater or lesser degree.

An extended epistemology of knowledge

Heron, in his exploration of knowledge introduced a model of holistic knowledge which "holds that propositional knowledge, expressed in statements that something is the case, is dependent upon three other kinds of knowing; practical knowing, or knowing how to exercise a skill; presentational knowing, an intuitive grasp of the significance of patterns as expressed in graphic, plastic, moving, musical and verbal art-forms; and experiential knowing, imaging and feeling the presence of some energy, entity, person, place, process or thing."(Heron J. 1996. p52) Most doctors, I believe, when considering this definition of knowledge would recognise the importance of practical knowing and presentational knowing in their daily professional lives. The practical skills involved in listening to the heart sounds take a long time to acquire and anyone who has made the effort to do so understands what has been obtained. Similarly, much diagnosis depends upon the 'intuitive grasp of patterns' and as medical students we all remember those teachers who had an uncanny ability to make the correct diagnosis on the flimsiest of evidence because they had intuitively recognised these patterns. I would like to extend this idea, away from the straightforward acquisition of medical skills, and suggest that there are other forms of practical knowing such as compassionate, cultural, organisational knowing that develop so subtly that one is almost unaware of acquiring them. For example, how do you acquire 'compassionate knowledge'?

I have to give bad news so often as a doctor that it would seem to me to take a truly insensitive individual who did not gradually obtain a more compassionate way of delivering such news. Without fully realising how it happens, I suspect that most acquire this skill in knowing what to say and saying it appropriately, although I am not aware of any study that has specifically looked at this. For example, there would appear to be a considerable difference between giving bad news to a single parent of twenty with breast cancer and an eighty year old widower with coronary artery disease. The subtle patterns that make up these differences and should lead to a more 'appropriate' way of delivering

this information in terms of outlook, use of metaphor etc. are ones that I would expect experienced doctors to recognise.

With this in mind, I began to look for other forms of knowledge, cultural, organisational and others, that permeates medical practice. In this respect Heron's definition of knowing is useful because it encourages one to extend the realm from which data is normally generated. Experiential knowing he saw as 'knowing, imaging and feeling the presence of some energy, entity, person, place, process or thing.' (Heron J. p 52, 1996) Here, I suspect, most doctors, including myself at onetime, would start to falter. Where is the place for 'presence of energy, entity, person, place, process or thing' in the scientific medical world of chloride ion transfer through membranes, double blind controlled trials and cisplatinum chemotherapy?

As I have already indicated, I was beginning to see that by placing contemporary medical practice in a historical and cultural context in a semi ethnographic fashion, I can 'see' connections with other belief systems of medicine from other countries and other ages. One cannot present conventional proof that such connections are present because it is only by recognising the *patterns* that are similar to both that the connections can be understood. As described earlier, I 'see' surgery in relation to sacrifice; I 'see' outpatients as religious temples. I understand these connections, these relationships, as operating at this 'experiential' level. Understanding these experiential insights doesn't come easily.

If I talk to doctors about any similarity between contemporary medicine with other medical systems, some immediately lose interest possibly because they do not wish to see themselves as being part of a wider 'more primitive' system of healthcare or they disagree with me. There seems to be no place for such interpretations within the specific theory and values of contemporary medical science. Nevertheless, if I accept for a moment the assertion that knowledge is theory and value driven, it suggests that it has to be appropriate for other kinds of knowledge, for example the patient's own medical

knowledge, to be introduced into the decision making equation. It can no longer be dependant upon one perspective, the medical perspective of the doctor.

The sections below represent some early thinking on different forms of knowledge as they relate to me as a medical practitioner. They are early articulations at identifying different forms of mostly practical knowledge, perceived as important, that cannot be expressed through the framework of a positivist paradigm. Although they seem naïve now, they represent part of the 'audit trail' of thought connecting the various sections of the thesis together. I acknowledge that many of the inferences are unconnected with supportive data and most are self-referencing, but I have taken the decision to include them because they form part of the process of personal change and are presented as 'evidence' that this took place.

Compassionate knowledge

Compassionate knowledge, knowing how to care or appear to care (appearing to care is probably organisational knowledge) in an authentic manner is non-authoritative and non-directive. It could also be argued that it is in practical medical terms ineffective. For example, if faced with the victim of a serious care accident someone with just compassionate knowledge would be ineffective. However, compassionate knowledge permits insights into how people react to medical events that shape their attitude towards illness, life, death or whatever. These insights, I have found, will only be obtained when the doctor genuinely exhibits compassion in this way. I have obtained such insights about my own attitude towards death on those occasions when I have been more genuinely involved as a doctor. I cannot as a doctor become compassionately involved with every sad experience I encounter, but on those occasions I do, I am aware of learning something new by doing so and this increased understanding permits me, I believe, to be more useful on the next occasion I become involved.

When doctors who have not obtained a degree of compassionate knowledge have to give comfort, it can be highly destructive. I have an acquaintance who lost her husband

tragically in an accident and one of her continuing causes of pain was reliving the 'brutal and inhumane way', as she saw it, she was informed of his death.

Organisational knowledge

Organisational knowledge is knowing what to do within an organisation; who to contact, how to find the sources of expertise and information, etc. that characterises hospital life. It is potentially a little more directive in its quality. I see it as the sense that the organisation subtly guides and controls what happens within it. When I first joined a new hospital, I became aware that I hadn't acquired such knowledge, and as a consequence felt organisationally lost for a month or two. Each year in August newly qualified doctors arrive on the wards. Because they do not possess this organisational knowledge they are to begin with not very effective and seem to feel disempowered. As patients and new qualified doctors wander around corridors looking for x-ray departments, outpatients, etc. they are everywhere surrounding by hospital staff apparently purposefully and knowledgeably striding to their destination in a way the suggests that 'I am part of this organisation and you are not.' When patients become familiar with hospitals in this sense, they are often described by medical and nursing staff as 'becoming institutionalised', suggesting that they know some of the organisational knowledge of the hospital and are often referred to as 'more difficult to handle.'

[Later in the thesis, I will discuss what happens when doctors become patients. They appear to use their organisational knowledge to obtain the treatment they need. This includes finding out who is the most technically competent, who has the reputation for making good decisions and utilising their organisational knowledge to move up a waiting list for surgery.]

Technical Knowledge

Technical or craft knowledge is practical knowledge of knowing how to do a certain surgical procedure and the manner by which surgeons judge their work. They know when

a procedure has been done well or not by a 'gut feeling' that it went well. It also includes the feeling that what was done is appropriate.

Ceremonial Knowledge

Ritual or ceremonial knowledge is different from organisational knowledge. It is the sense that certain processes are ritualised to the point where it can be difficult to change anything. The way an outpatient department is set up, the way the patient is prepared for surgery, the way the surgeon prepares himself for surgery makes it difficult to interrupt the process. I notice this when I go to a funfair. When I go on a roller coaster ride I am anxious up until the moment when the harness on the seats lock just before the ride starts, for from this moment onwards I can no longer do anything to influence what happens. I cannot get off the ride until it finishes. Hospitals have developed a similar sense of making it difficult to stop things from happening, once they have started. When patients arrive in the hospital on the morning of their surgery, there is a protocol of fasting, undressing, consent taking, lying waiting in a bed, premedication, collection by trolley that makes it difficult to stop the process. I feel this as a surgeon and notice how very difficult it is to re-evaluate the need for surgery at the last moment. It usually results in some anger from the patients when this happens even though the decision to cancel the surgery is clearly presented as being in their interests. I have little doubt that patients feel the same difficulty in questioning the need for surgery at this late stage and indeed may feel that the sense they have joined the 'roller coaster' of surgery, helps to overcome the natural anxieties we all feel about surgery. Ceremonial knowledge is very authoritative in nature and opting to work against accepted ritual or ceremonial practice can be difficult.

[Later I tell the story of 'Hannah' who decided to stop her surgery just at the point when she was due to go to sleep. This clearly was a disturbing event for her mother and the healthcare professionals involved. Appendix 3 is an account given by Valerie, who had a brain cyst aspirated on the ward. Everything inside her said that she shouldn't have it done but she felt powerless to stop the process.]

Sacrificial Knowledge

Sacrificial/ Pagan Knowledge is an understanding that underlying the medical interaction is an archetypal level of deep-seated need for something else. At this level it may be related to marking certain points in life; transitions from childhood to adolescence to adulthood to old age to death. There may be equivalents in religious practice, in education, in workplace practices, such as confirmation, graduation and retirement.

How, in the early stages, did I begin to consider the ways in which all these different epistemologies connected with one another? Initially it was by a process of compartmentalisation. In the same way that I, as a researcher, was conducting a dialogue with these new epistemologies, I saw this as representing a dialogue between head knowledge (positivism) and gut knowledge (all other perspectives). **Figure 3** represents in simple diagrammatic form how I began to mentally conceive of this. I saw it as a two way dialogue so that what we present to the world as propositional knowledge is dependent upon this bedrock of difficult to describe and impossible to 'measure' qualitative knowledge. In making the assumption that this was what was happening, I saw each person, each doctor, each patient having their own rules that govern how the two interrelate and influence each other for any given situation.

How did this simple model work for me in practice? It worked for me in a manner of different ways. Sometimes the appearance of an eardrum suggesting the development of serious ear disease (practical knowledge), will override all considerations and become the key ingredient in triggering off the decision to undertake surgery. Sometimes there is a pattern of disease, lifestyle, anxieties, previous experience, (presentational knowledge) that suggest that treatment with antibiotics may be appropriate for an ear infection when the published work suggest that this should be unnecessary. Occasionally, a father might donate his kidney to his child in order that they may live (sacrifice) when one biological argument would suggest that best thing is to have many more children. There are obviously innumerable other ways in which the propositional knowledge that we present

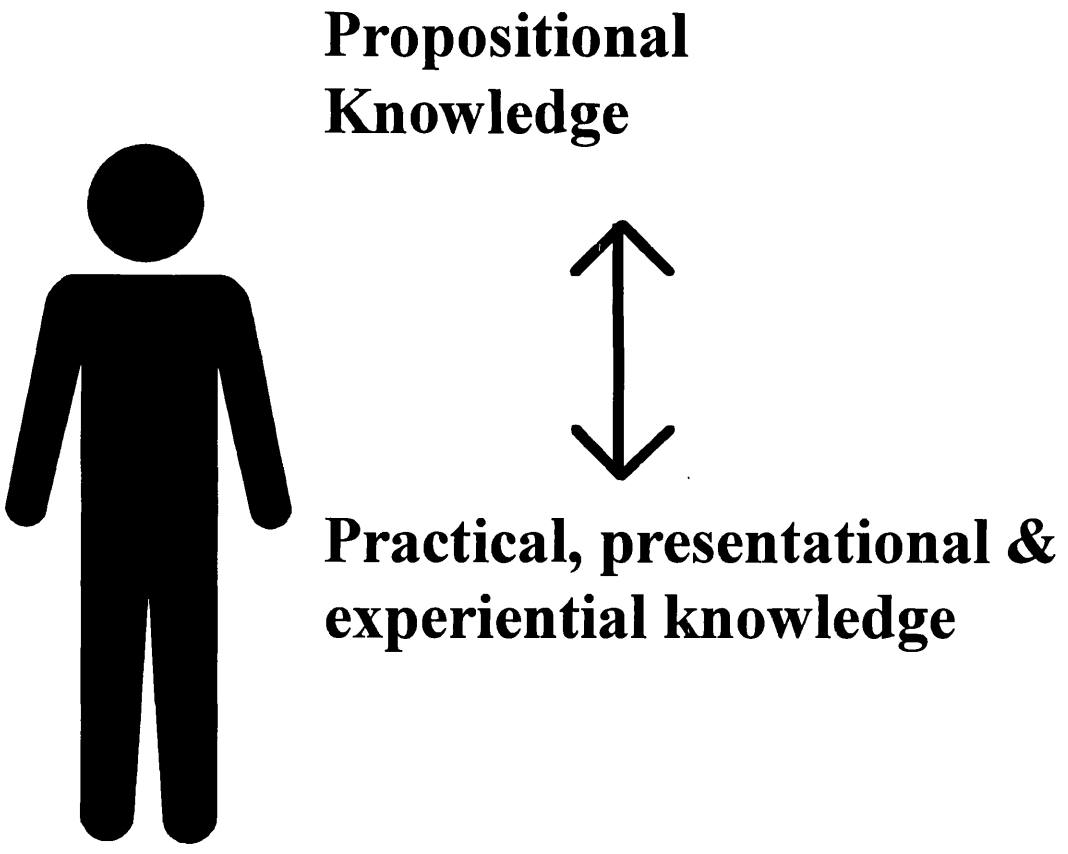


Figure 3.

This represents an early model of how I perceived different kinds of knowledge relating to one another. Propositional knowledge (or head knowledge) was engaged in a 'dialogue' with practical, presentational and experiential knowledge (intuitive knowledge)

to the world for decision-making purposes, can be influenced by underlying factors. What did this mean for me?

This meant that my whole belief structure that explained how decisions were made in the outpatient consultation was challenged. It was not simply a question of considering just the medical evidence but it became important to examine the assumptions that underpinned what constituted evidence. Decision making shifts from understanding knowledge to understanding knowledge in context. This is a clear shift from the positivist paradigm of time and context free generalisations to the naturalist paradigm of time and context bound statements.

The thesis so far has shown some of the areas of interest that were relevant to my practice I wanted to explore. The next section will look at the methodology I used during the course of the research to explore these issues and to help me engage in what I now describe as a shift in professional operating paradigm. This was a shift from a paradigm that acknowledged only one kind of scientific knowledge to one that incorporates this and at the same time recognises and pays respect to other forms of knowledge held by healthcare professionals and the patient. The belief was that engagement with these methodologies might lead to a form of clinical consultation that respected the unique situation of the doctor patient interaction.

METHODOLOGY

Introduction

I am obliged to begin this section by asking to what extent this is a retrospective reconstruction. In one respect everything that is written is a retrospective reconstruction and rationalisation but in this case I am revising my account of a methodology some time after its enactment. How can I hope to justify this and maintain credibility? In the first submission I acknowledge that I was overtly espousing a co-operative inquiry methodology but in retrospect I can claim to understand more clearly that I was trying to work as an action scientist/ inquirer within a research and practice framework outlined in the introduction and repeated below. This has meant that I have been able to look at the project not only with a level of hindsight but also with a greater level of insight. It follows that I acknowledge that certain things were not done well.

It would be useful to remind the reader of the conceptual model that formed the basis of my research design. This works at three levels. First of all there is the need to continue to operate as a practical doctor, actually *doing* things and utilising effective biomedical understandings and treatments that have been derived from the positivist tradition. Secondly, I acknowledged the need to place such knowledge in context, to provide freedoms for both practitioner and patient to question the appropriateness of such treatment. Thirdly, I operated as a 'researcher' with an awareness of the ontological position I was adopting as a practitioner. This conceptual model was summarised in the introduction section and is reproduced here.

1. In my position as a doctor I operate at one level as a positivist (positivist theory generating data production).
2. At the same time I have tried to work as a reflective practitioner/ action inquirer (constructivist theory underlying nature of data and data production)

3. And finally as a researcher I try to develop an awareness of the ontological position I am adopting. This may be described as theory behind theory in that it represents an awareness of the assumptions circumscribing a particular paradigmatic position.

In attempting to show how this was developed, the methodology section is arranged in four broad sections. Each section addresses significant decisions that need to be made when developing an overall, practical research design. These comprise;

1. Ontological and epistemological issues in relation to a research question
2. Linking research questions, epistemology and methods
3. Ethics, morality and politics of the research process
4. Producing a practical research design

To track progress through the methodology, the reader will be briefly reminded of this overall structure as each of these main sections is commenced.

I would like to make two further points that will clarify what happened. Firstly, it is important to know that I set out in 1990 to investigate decision making using a co-operative inquiry methodology. This inquiry group of hospital doctors, including myself, will be discussed in detail in Section 4, 'Producing a Practical Research Design'. In 1992, I took the research decision that a co-operative inquiry research methodology was proving to be insufficiently helpful in the clinical context and shifted towards an action science/ inquiry methodology. Secondly, central to the research task is the integration of medical (quantitative) knowledge with other forms of knowledge (qualitative) and I therefore perceived the need to understand a range of methodologies that were typical of methodologies to be utilised within different paradigmatic perspectives. These different approaches came to be broadly reflected in different clinical consultation styles and outlined in the clinical frameworks discussed in the next section, 'Reflective Clinical Practice'. Consequently, this review of methodology aims to place epistemology and methodology in paradigmatic context, as a result, it is not until the final section, 'Producing a practical Research Design' that I reconstruct what I set out to do.

Section 1

Ontological and epistemological issues in relation to research questions.

The conceptual research model with three levels of understanding suggests a complicated way of appreciating what happens. The model depends upon a clear understanding of the ontological standpoint that notices, generates and analyses data. For this reason the first questions to ask are;

What possible paradigmatic approaches are there?
What is my ontological perspective as a researcher?

A positivist would enter his research at the point of methodology but in qualitative research it has been argued that "questions of method are secondary to questions of paradigm" (Guba & Lincoln 1994 p105). This point of view suggests that it may be necessary to carefully reconsider the basic paradigmatic approach and ask; What is meant by 'paradigm' and what are the elements upon which a paradigm is constructed. A paradigm "may be viewed as a set of basic beliefs (or metaphysics) that deals with ultimates or first principles. The beliefs are basic in the sense that they must be accepted simply on faith (however well argued); there is no way to establish their ultimate truth." (Guba & Lincoln 1994 p107) Each paradigm encompasses three elements with a coherent attitude to the epistemology, ontology, and methodology relevant to that paradigm. Epistemology asks questions about the nature of knowledge and in particular the relationship between the inquirer and the known. Ontology raises basic questions about the nature of reality and methodology focuses on how we gain knowledge about the world. (Denzin & Lincoln 1994 p99-104)

Guba and Lincoln have outlined four paradigmatic approaches:

Positivism
Postpositivism
Critical theory and related ideological positions
Constructivism .
(Guba & Lincoln 1994 p105-117)

Each of these is defined by a stance on the three positions of ontology, epistemology and methodology. In positivism the basic posture is reductionist and deterministic. The investigator and the investigated 'object' are assumed to be independent entities with a methodology that is perceived as experimental and manipulative. Findings are believed to be 'true' and when threats to the validity (influence on either the investigator or object) are recognized, various strategies are followed to reduce them. The emphasis in methodology is one that permits robust replication. This ontological stance is one that is constantly reinforced by most medical research literature with its emphasis on the importance of double blind, randomised, controlled trials to generate data. In some respects the post-positivist stance is a watered down version of positivism. The ontology is essentially the same but is only regarded as imperfectly apprehendable because of basically flawed human intellectual mechanisms and the fundamentally intractable nature of phenomena. Adherence to the concept of dualism (researcher/ researched) is largely abandoned but 'objectivity' remains a 'regulatory ideal'; special emphasis is placed on external 'guardians' of objectivity such as critical traditions and the critical community. The emphasis in the methodology is on 'critical multiplism' (a refurbished version of triangulation) as a way of falsifying hypotheses. Inquiry takes place in natural settings and the collection of situational information and discovery are key elements in inquiry. Any findings are regarded as 'probably' true.

In contrast to positivism and post-positivism, critical theory represents a genuine shift in ontology. Critical theorists and those with related ideological positions adopt a position that has been described as 'historical realism', where "a reality is assumed to be apprehendable that was once plastic, but was, over time, shaped by a congeries of social, political, cultural, economical, ethnic and gender factors, and then crystallized into a

series of structures that are now taken as 'real', natural and immutable." (Guba & Lincoln 1994 p110) The conventional distinction between ontology and epistemology now disappears. The investigator and the investigated object are assumed to be interactively linked, so that the values of the investigator inevitably influence the inquiry. Such findings are inevitably regarded as value mediated. The methodological approach requires a dialogue between investigator and the subjects of inquiry; that dialogue must be dialectical in nature to transform ignorance and misapprehensions into more informed consciousness. (ibid)

Social constructivists insist that "all forms of knowledge, including scientific knowledge, produce images of the world that then operate as if they were true." (Gergen, K.L. 1985 266-75). They end up "being more sceptical of how science operates...and will insist that there is always a moral aspect to research." (Banister, Burman, et al. 1994 p9) All research questions are structured by personal and political interests that need to be explored rather than hidden away. The position means that exploration in research not only "respects the specificities of each case (idiographic research) but should also explore the particular meanings that are produced on this occasion (hermeneutic research). Knowledge creates as well as describes the world." (ibid)

Heron and Reason, (Heron and Reason 1997 p274-294) analysed the constructivist vision and became concerned at the absence of a place for "experiential knowing; that is by acquaintance, by meeting, and by felt participation in the presence of what is there" and have recently added a fifth paradigm. They call this paradigmatic stance 'participatory' and identify its paradigmatic position in the same terms as Guba and Lincoln. A participatory ontology appears to be only understood by experience; "knowers can only be knowers when known by other knowers", but in particular draws attention to the tacit rules of language and behaviour that govern any "mutual experiential knowing and understanding between people." At the epistemological level, knowledge is "inter-subjectively" shaped with four interdependent ways of knowing; experiential, presentational, propositional, and practical. Experiential knowing is "direct encounter, face to face meeting: feeling and imaging the presence of some energy, entity, person,

place, process, or thing...creative shaping of the world." Presentational knowing "emerges from and is grounded in experiential knowing and is evident in our intuitive grasp of the significance of our resonance with and imaging of the world." This is "symbolised in graphic, plastic, musical, vocal and verbal forms." Propositional knowing in conceptual terms is "knowledge by description of some energy, entity, person, place, process or thing. It is expressed in statements and theories that come with the mastery of concepts and classes that language bestows." Finally practical knowing is knowledge demonstrated "in a skill or competence" and it represents the fulfilment of the three prior forms of knowing, bringing them to fruition in "purposive deeds". The methodology, by implication, has to be experientially centred, and usually takes the form of collaborative versions of inquiry.

Heron and Reason recognised that the three basic constructs of paradigms, ontology, epistemology and methodology, concern themselves only with the nature of 'truth' and do not consider the question of 'values' as part of the definition. To overcome this objection they add a fourth arm to their paradigm analysis, which they call 'axiology' and advocate that "the participatory paradigm answers the axiological question in terms of human flourishing, conceived as an end in itself." This fourth arm suggests that notions of underlying purpose, such as 'justice', are missing from conventional paradigms and they suggest it is important to introduce such values into research when previously they have been conspicuous by their absence.

Are these paradigms necessarily in conflict? Is it possible to accommodate these several views within a single conceptual framework?

Proponents of positivism and postpositivism take the position that all paradigms can be accommodated within some common rational structure to which all questions of difference can be referred for resolution. This posture is "reductionist and assumes the possibility of point by point comparisons." Proponents of critical theory, constructivism and participatory paradigms affirm the incommensurability of these three paradigms with positivism and postpositivism and take the view that "basic beliefs of the paradigms are

believed to be essentially contradictory." (Guba & Lincoln 1994 p116) For constructivists, either there is a 'real' reality or there is not and these two views cannot be logically accommodated because inquiry is either value free or it is not, realist or relativist; such contradictory positions cannot co-exist.

The conceptual three level research model I have outlined suggests apparently irreconcilable differences and these differences need to be addressed. It seems to me that each paradigm represents a set of beliefs (and assumptions) that provide the background against which any study operates. The extent to which each of these elements of epistemology, ontology and methodology is aggregated around each set of assumptions will vary. In the positivist paradigm, the epistemological and methodological position will be very proscriptive so that any departure from the norm will be seen as a potential threat to the validity of the result. The more descriptive nature of epistemology and methodology in the constructivist paradigm will permit a greater degree of tolerance; indeed so much so that in a sense there is no body of procedure that can be appealed to in the case of disputes.

The part of me as a positivist affirms that the positivist approach to clinical medicine is sound. I am witness to a progression of knowledge that is first of all based an anecdote (e.g. case histories), then anatomical basis (e.g. clot in the coronary arteries as an explanation for heart attacks), physiological understanding (e.g. mechanisms of clot production in heart attacks) and finally explanations at the micro-cellular RNA and DNA level. As the epistemology departs from one of anecdote to the 'DNA level', the robustness of the positivist model appears to be strengthened. The problems I have described so far as a clinical practitioner can be seen as attempting to utilise constructivist epistemologies within a positivist methodology. At the paradigmatic level the two are not inherently in tune with one another and the resulting dissonance can be overlooked or explored (I am not necessarily advocating at this stage that exploration is the right thing to do).

Some might argue that the first requirement in any research strategy is to develop an approach that is inherently coherent; the ontology, epistemology and methodology pay consistent attention to a recognised paradigm. Any departure from this position would appear to break a key principle of investigative science. In order to comply with this academic requirement I need to accept for a moment that explanation can be formulated within one single paradigmatic approach. This means that for the purposes of much of this study, I espouse a constructivist position but I do not intend to be confined to this paradigm forever, indeed cannot be. I still fully recognise the effectiveness of positivism and since my fundamental position as a researcher claims that I have developed an awareness of my paradigmatic position (my 'ontology' is an awareness of paradigm) there are two requirements to fulfil. Firstly I need to demonstrate that I understand what is meant by an awareness of paradigm and secondly justify this from a philosophical standpoint.

It is not easy to do either. Firstly, I 'know' from my experience that there are times when I consciously adopt a positivist stance and hold it. Twice a year I run a course at Oxford that operates almost exclusively within the positivist paradigm. It is marketed as a course that adheres to 'evidence based' medical principles. When participating in the course, which includes analysing research papers, I am aware that I am operating within a set of agreed rules and assumptions. It is like playing a certain kind of intellectual game. By contrast this body of work, I hope, demonstrates at least some evidence of being able to operate as a constructivist. This switching around doesn't appear to create a problem in my own mind, yet within the paradigmatic framework so far described would seem to be untenable. So how can I justify this philosophically?

My position suggests that I am appealing to another, superior vantage point from which to view the different paradigms but I am not. When one considers as a group the five paradigms described so far, it is hard to escape from the notion that they represent an *evolutionary* approach to theory. Positivism seems to evolve into post positivism, into critical theory, into constructivism and into participatory paradigms. After all, it was Kuhn who argued that when scientists become stuck in one paradigm they invent another

one to make progress. He could find no logical foundation for this shift and it was left to Foucault to rejig this idea by introducing the idea of history of concepts. He advocated that, unknown to each other, naturalists, economists and grammarians employed the same rules to build their theories. He applied the term 'archaeology' to the process of excavating unconsciously organised sediments of thought. Archaeology ignores individuals and their histories, it prefers to excavate impersonal structures of knowledge. He coined the term episteme to define the underground grid or network, which allows thought to organise itself. Each historical period has its episteme, which limits the experience, what is knowledge, what is truth and governs each science in any one period. The Renaissance episteme was resemblance and the Classical episteme was representation. The episteme for the modern period is 'man' for it is *through* man that knowledge is possible in the experience of life. (Cutting 1994 p7)

It can now be seen that Kuhn and Foucault approach the problem of theory from different standpoints. Kuhn advocated that theories are interpretations of data and therefore define the concepts in terms of which data is understood; that is what a paradigm is, a set of assumptions that circumscribe data and make it manageable. Others such as Foucault and Canguilhem adopted a different approach that distinguishes concepts that interpret scientific data and the theories that explain them. "Concepts give us preliminary understandings of data that allows us to formulate scientifically fruitful questions about how to explain the data as conceptualised. Theories then provide different and often conflicting answers to these questions." (Cutting 1994 p7) The example usually given to illustrate this is the theory of motion. After Gallileo introduced a new concept of the motion of falling bodies (i.e. all bodies fell at the same rate independent of weight, a different concept from that of Aristotle), he, Descartes and Newton provided competing theories to explain the motion. If the concept is regarded as a function of theory, their history will be identical but they can be separated out. For example, Canguilhem demonstrated this in the history of reflex action. The concept of the reflex action is at the heart of modern mechanistic theories in physiology but Canguilhem shows that the modern concept of the reflex is fully present in the distinctly non modern vitalistic physiology of Thomas Willis. (Rouse 1994 p92-114) Foucault develops this idea in The

Order of Things and The Birth of the Clinic when he traces the history of the concept of physical illness. He links language, biology and economics and goes on to maintain that fundamental philosophical concepts such as resemblance, representation and man pervade all disciplines of a given period. (ibid)

I hold my current position by taking the view that there is nothing fundamentally 'true' about paradigms. They all represent constructions, indeed, I see such constructions as essentially *evolutionary* in much the same way as we have developed biologically-like biology it is an evolution of complexity. It forms the basis whereby I can justify to myself that switching between paradigms is more than disguised constructivism and simply reflects different points in the evolution of epistemology. Where one sits on the paradigmatic seesaw depends upon appropriateness and appropriateness is justified in a number of ways.

At the heart of the problem of justification is the question; How does anyone interpret methodological statements? There seem to be three options; description, convention and contingency. (Honderich 1995 p434) A conventional interpretation acknowledges that there is a body of uncontentious outcomes linked to a recognised methodology. For the purposes of this study I cannot find a recognised methodology and so I have abandoned a conventional approach to justification. If an interpretation is descriptive, one cannot appeal to an uncontentious body of knowledge but instead appeal to a virtuous spiral of understanding that permits 'better' questions to be asked and 'better' methodologies to be developed. There may be some evidence of this in this thesis. Finally, if ones interpretation is intuitive and founded upon assessments of methodologies based upon past success or not, it still leaves the problem of convincing others of the rationality underlying it (if such a rationality exists). This is at the core of any charge of 'self referencing'. I would argue that whilst effectiveness, however that is defined, does not lend itself to rational description, for someone in the midst of action it can be difficult to ignore. In any situation, effectiveness is therefore judged according to the assumptions of the paradigm in which one is methodologically operating. For example, if I operate within a contemporary medical paradigm of positivism, I might judge life expectancy,

with or without treatment, as a parameter of effectiveness, but such a position might chose to wholly ignore such considerations as quality of life a parameter of a different paradigm. There is a counter argument that paradigmatic inconsistency may be acceptable if one has at the very basis of one's belief the idea that the whole foundation is arbitrary anyway (the episteme argument) and that periodically this foundation will change as society shifts to some other era of enlightenment.

Bateson (Batson 1997) offers an analysis that suggests that this approach is credible. He divided learning behaviour into levels, levels one, two and three. Working as a positivist, would be equivalent to working at level one. Developing my clinical practice as a reflective practitioner would be equivalent to working at level two and most research is conducted at this level. Level two learning frames would suggest that constructivism, or positivism or any other paradigmatic viewpoint was the only 'right' way to see the world and that standards for determining what is relatively true resides in community consensus (Heron, Reason 1997 p283). Level three suggests that each of these positions is regarded as only one way to see the world. Learning level three is a position in which the mind can choose its premise of understanding and action and can detach itself from all frameworks to peer into and reflect on their pre-suppositions. It might be argued that a reflective practitioner would want to, and could, do this. I would argue that whilst a reflective practitioner might shift to positivism from time to time (emergency medicine in an unconscious patient) it is the position of a researcher who asks questions about the appropriateness of this paradigm shift, that characterises level three learning.

The examiners have forced me to realise that I am working in level three in a number of different paradigms at the same time;

1. The positivist world of a doctor-looking in someone's ear.
2. The social constructivist paradigm of grounded theory in trying to learn from people out there. Researching into how to do this with better skills
3. The fully self-reflective paradigm that permits an awareness of different ontological perspectives.

I am using a research stance to look at practice in those different domains so that at different moments I pay more or less attention to each of these. This may result in shifting from being doctor to reflective practitioner to being researcher.

What are the practical considerations in adopting a paradigm as a standpoint to enter research?

Each of the five main paradigms outlined earlier has a different ontological, epistemological and methodological position in respect of the research qualities required in certain key features. These are principally

- Level of participation in the research of the various actors
- The nature of the data
- Who makes sense of the material
- Level of self reflectiveness required by the researcher
- Level of self referentiality

At this juncture there is the need to consider in very general terms the importance of each of these parameters in determining a paradigmatic starting point. In this respect there is a considerable variation across the paradigms. As one moves from positivism to participatory paradigms, the difference between researcher and researched changes from being clearly distinguishable to becoming somewhat blurred and the degree to which the 'researched' participates in the researched activity increases. The data shifts from quantitative to descriptive. The sense making in positivist research is entirely undertaken by the researcher but in constructivist and participatory forms of research the data generation and the sense making is typically made by all the actors as well as the researcher. In these paradigms there are hierarchies of institutional, political and medical power as well.

Perhaps most important of all is when shifting from quantitative to qualitative research positions there is an increasing emphasis on the role of interpretation. According to

Woolgar (Woolgar, S 1988) the gap between objects and our representation of them appears in three forms and has been termed the 'methodological horrors'. They comprise three problems:

a) **Indexicality**, in which an explanation is always tied to a particular occasion or use and will change as the occasion changes;
b) **Inconcludability**, in which an account can always be supplemented further and will continually mutate as more is added to it; and
c) **Reflexivity**, in which the way we characterize a phenomenon will change the way it operates for us, and that will then change our perception of it.

Indexicality

The usual strategies to counter this include "appealing to a hierarchy of existing scientific knowledge that should not be questioned, treating the problem as a technical one or as a trivial difficulty, or deferring the task of dealing with it, leaving to others to solve it as a philosophical problem." (Banister, Burman, et al. 1994 p11) Failure to address these issues adequately is likely to lead to failure to satisfy validity criteria and contemporary qualitative research prefers to confront them. The approach to the problem of indexicality is to "turn it into an aspect of the research itself." Since explanations change as the research setting changes, then attempts are made to "theorize" this. The hope is that the theory, or some feature of the theory, may have more general application. As a doctor I have probably instinctively, though with no awareness, tried to do this all the time in the clinic. I have theorised (or hypothesised) the medical settings in which treatments appear to work. To accept these arguments means that it is necessary to reformulate what is understood by validity and reliability. In quantitive research these terms depend upon the possibility of replicating good research but in qualitative research no attempt is made to do this. There is an acknowledgement that any repetition of the work is necessarily a different piece of work. Any meaning that is produced in the course of research is something that has to be followed and recorded carefully and sensitively, and an account of the process of tracing and presenting the analysis as the 'results' of the study is an account of change. This may involve change in the research tool itself and my account of

my research hopefully demonstrates this. I commenced my research espousing an overt co-operative inquiry but shifted to an action science inquiry methodology as the study progressed. This was recognised and acknowledged when the thesis was rewritten. Underlining all this is the idea that any "findings of the study are as fragile and mutable as real life," (ibid) and, like real life, such findings include an analysis of failure.

Inconcludibility

Engaging in qualitative research starts a process that seems to have no logical end point. This is seen as an advantage and qualitative research "draws its strength from the ways in which accounts of action and experience reinterpret and understand facts anew, such that their shape, function and very nature seem to change." (ibid) This means that one should welcome the opportunity for others to supplement their account. This has particular implications in respect of sample size. Because the emphasis is on complexity, it is no longer deemed a validity affirming requirement to have large sample sizes and it can even mean that single case studies are acceptable provided the description is rigorous enough.

Reflexivity

Reflexivity acknowledges that "the ways in which we theorize a problem will affect the ways in which we examine it, and the ways in which we explore a problem will affect the explanation we give." (ibid) Qualitative research attempts to overcome this by "an exploration of the ways in which the subjectivity of the researcher has structured the way it is defined in the first place". Reflexivity is seen as both personal and functional. Personal reflexivity is an attempt to "reveal rather than conceal the level of personal involvement and engagement." This approach places the values of the researcher at the centre of the process of understanding rather than attempts to deny that such bias exists. This approach may mean developing a careful balance between a need to be critically subjective to empathise with the participants but at the same time be "aware of our own experiencing in order to achieve a balance between subjectivity and objectivity". Failure to do this properly may lead to findings that "may merely be a reflection of our own subconscious issues disturbed by the research." (Bannister, Burman et al 1994 p151) The balance between subjectivity and objectivity may be more easily aided by discussion in

research groups of the issues raised as a means of heightening awareness. The postgraduate research group provided a forum for this process to be developed. Functional reflexivity is the "continuous, critical examination of the practice/process of research to reveal its assumptions, values and biases. The focus is on how *who* we are directs and shapes the course of the research." (ibid) This is an acknowledgement that research and self cannot be separated from one another, so that research will include an exploration of the researcher's background. This is largely developed by the use of a reflexive diary.

Since much of my research and thinking takes place in a clinic, a private space, how do I in practice develop a process that permits some of the methodological horrors to be confronted? This potentially self referencing position suggests that a methodology that was based around the clinical process alone would be insufficient. For example if my sole methodology was based around action science, and I undertook this as an isolated researcher with no access to supervision then it is unlikely that I would develop sufficient reflexivity. In the final analysis my methodology included significant input from the postgraduate research group at Bath, a group of qualitative researchers, which became a medium in which reflexivity issues could be addressed and challenged.

The methodology section so far has addressed the question of basic paradigm position as a researcher. Before individual methodologies can be considered in detail, it is necessary to consider two important issues. What might be regarded as data or evidence within the clinical encounter and what are the research question or questions? The remaining two sub sections of section 1, devoted to ontological and epistemological issues, concentrate on these issues.

What might be regarded as knowledge or evidence within the clinical encounter?

This section approaches the issue of knowledge or evidence from three perspectives. Firstly, a recap of knowledge from the different ontological positions described in the previous section, emphasising that part of the process of examining the nature of data

became a means whereby my ontological position shifted. As I increasingly believed and understood that data was theory driven, this 'data' generated a paradigm shift towards constructivism. Secondly, it includes an examination of the nature of professional knowledge, especially practical knowledge. Finally, it examines knowledge about knowledge, which leads one to ask; What is meant qualitative research?

Epistemology according to different paradigms

Knowledge has been defined "as a body of uncontradicted beliefs, which is socially and politically constructed." (Denzin 1983 p139) This is at heart a constructivist's perspective of knowledge because implied within the definition is the notion of the agreed socially and politically generated assumptions that characterise each of the paradigms anyway. This leads one to consider the nature of knowledge according to the different ontological perspectives of positivism, post-positivism, critical theory and constructivism. Positivists regard as facts or laws only those "verified hypotheses" that have been accepted. Reference is made to what is accepted by positivist as a body of non contentious data. Post positivists water this down a little, continue to pay lip service to positivism and take the position that "non-falsified hypotheses can be regarded as probable facts or laws." (ibid) Critical theorists begin by paying attention to the cultural and historical context of 'fact' and regards facts as "a series of structural/historical insights that will be transformed as time passes." (ibid) Finally, the diversity that confronts constructivists is reflected in the description of facts as "those constructions about which there is relative consensus (or at least movement towards consensus) among those competent to interpret the substance of the construction." (ibid) Not only is the idea of multiple perspectives important but perspectives that seemingly disagree can coexist when equally competent (or trusted) interpreters disagree. This difference is an acknowledgement that the social, political, cultural, economic, ethnic and gender factors that differentiate the interpreters influences the constructions they generate. This means that consensus is subject to continuous revision and is most likely to occur "when relatively different constructions are brought into juxtaposition." (Guba & Lincoln 1994 p113) It is their epistemological positions that most differentiate critical theory and constructivism from the other two paradigms.

In this work the fundamental clinical interaction is the interview, which may be structured or unstructured. From this data source, knowledge and understanding of what is happening, and what we consider as 'facts' are derived. It follows that there is a process whereby this interaction is transformed into 'facts' and this transformation is subject to certain rules that validate this transformation and hence validate these 'facts'. This obviously is dependent upon one's paradigmatic position. From a positivist viewpoint it is regarded as important to isolate data from its context and the more isolated from its context this data appears to be, the greater the theoretical rigour such a study can claim. Within such a positivist ontology, meaning and purpose for example would appear to play no part in an analysis of any data and are excluded in the analysis. From a constructivist viewpoint, meaning and purpose play a pivotal role in an analysis of the same data. This difference is reflected most obviously in the aim or purpose of an inquiry when undertaken within the framework of positivism or constructivism. In positivism the aim of the inquiry is *explanation* whereas in constructivism the aim of the inquiry is *understanding and reconstruction*. (Guba & Lincoln 1994 p113) The constructivist position suggests that what are considered 'facts' derived from data such as a clinical interaction is dependant upon the paradigm through which the data is viewed, that is theory is data driven or data dependent. Facts are only facts when viewed through a particular theoretical window, a position which undermines the 'objectivity' of facts. (Guba & Lincoln 1994 p107) Some commentators would extend this and insist that all forms of knowledge, including scientific knowledge, produce images of the world that then operate as if they were true. (Gergen 1985 p266-275) Such a position adopts a more sceptical stance of how science operates and will insist that there is always a moral aspect to research. This morality starts right at the beginning, including research questions, which are regarded as structured by personal and political interests that need to be explored rather than hidden away. (Banister, Burman, et al. 1994 p9)

The theory driven nature of data is an assumption about data that constructivists make about paradigms. I am not sure that every positivist, whose assumptions may be contingency based, would agree. A positivist engaged upon 'quark' research may have

difficulty seeing his or her research in any other way other than basic, objective, fundamental research whose political and moral content is nil. Since very few people are in a position to offer a perspective on 'quarks' this position is never seriously challenged.

The constructivist would also argue that values and facts are interdependent. Theories are themselves value statements. Thus putative 'facts' are viewed not only through a theory window but through a value window as well so that the "value free posture of the received view is compromised." (Guba & Lincoln 1994 p107) This becomes especially important to recognise in practice related research because knowledge applied in practice suggests purpose. "Knowledge should speak to the forming of purposes, not just the means by which to achieve them. A science of practice must take up the question of choice, and the question of choice necessarily involves the forming of purposes...Once we consider purposes, the questions of value can no longer remain peripheral." (Argyris, Putnam, et al. 1985 p234-235)

This suggests that the ethical and moral position of the constructivist shapes the way the research is conducted, from the formulation of the research question onwards. This is especially relevant in two ways to my conceptual research model because my research also involved a clinical activity; I am trying to *do* something. Firstly in the level of participation of other actors, especially patients, envisaged as appropriate in the research. Participation might raise difficult ethical issues if understandings lead to insights that suggested action was deemed appropriate by the researcher for or on behalf of the participants. If these clinical facts are value dependent, it suggests that any researcher may be inadvertently generating 'facts' that are simply a reflection of their moral and political stance. If then as a positivist doctor I believe that a particular course of clinical action is in the 'interests' of patients (a value judgement made by me) how do I reconcile this with an approach to research that is espousing a degree of mutuality? As a consequence of this, I need to consider how, as I shift to different ontologies, do I ensure safeguards are in place that make sure that patients come to no harm through inappropriate paradigm experiments?

Secondly, how do I shape the research in respect of language and its relationship with power? The issues determining action are mediated through the use of language. The biomedical explanation that we take to be medical knowledge is a positivist construction reached by transforming the everyday language that patients use to describe their complaints into medical syntax. This transformation is largely under the control of the doctor. It is one opportunity for a doctor to express his or her power by transforming such information according to his or her values. This includes their epistemological position. If this position is a unitary positivist stance on the world, then this transformation can chose to ignore any information that the patient offers that appears to lie outside such a hegemonic position. This means that the decision to adopt a constructivist ontology means re-appraising this process and to consider more sensitively information that the patient offers that appears to fall outside the positivist perception of knowledge. Furthermore, this needs to be included as a factor that determines outcomes and shown to do so.

This approach carries with it certain risks. It is more than simply becoming a sensitive doctor because there may be moments when action is dependent upon attention to this information. If my insights at a clinical level suggest that a certain action is very much in the interests of the patient, what do I *do* if their own interpretation suggests otherwise. This particular situation is highlighted in the stories encountered in Appendix 1 and 2. The conventional wisdom suggested that treatment was appropriate for both these patients but they, for various reasons, felt that it was inappropriate. If, as a doctor, this value position had reflected itself forcefully in the way the options were presented to the patient (i.e. if you don't have this treatment then the manner of your death will be especially unpleasant) then this process is failing to pay due regard to the status of their wish not to have surgical or radiotherapy intervention. Thus an awareness of the status of 'facts' as theory and value driven, immeasurably complicates the clinical landscape.

The conclusion I reach is that any methodological model I develop must pay due regard to the problem of the value content of data. If I uncritically slip into constructivism, so that every viewpoint has the same weight, then I fail to appreciate the risk that this

strategy places all parties. I can adopt a stance of a constructivist as a reflective practitioner but I need to have an awareness of my ontological stance as a researcher in order to be more aware of what I am doing. This forms the basis for adopting the three level conceptual model, which includes an awareness of the positivist position as a safeguard against inappropriate action on my part. The second safeguard was the juducious use of a second opinion, an option explored by David in Appendix 1.

How does knowledge accumulate?

When considering a paradigm stance, one also considers the manner in which knowledge is expected to grow, because knowledge also has to accumulate in a way that appears convincing to others. In the positivist and postpositivist paradigm, knowledge accumulates by a process of accretion, adding to the growing 'edifice of knowledge'. After a while, generalisations can be made, with predictable confidence, to a population of settings. For the critical theorist, knowledge grows and changes through a dialectical process of historical revision that continuously erodes ignorance and misapprehensions to enlarge more informed insights. For the constructivist knowledge accumulates only in a relative sense through the formation of ever more informed and sophisticated constructions via the hermaneutic/ dialectical process. An important mechanism for the transfer of knowledge from one setting to another is the provision of vicarious experience, often supplied by case study reports.(Guba & Lincoln 1994 p114)

One significant feature of positivism is to establish external validity by generalising any finding to other 'similar' populations. For example, a study undertaken in the Postgraduate Hospital, Hammersmith is expected to be generalisable to one of my clinics in Frome, a small community hospital in Somerset. It is part of the politics of the power of positivism that such transferrability is assumed and is one way that the institution of medicine exerts its disciplinary power through its research and organisational structures. It dictates what constitutes knowledge and the way it should grow and be applied. The generalisability concept of positivism was deeply ingrained within my way of looking at knowledge and was in my experience very hard to let go. When I believed that I was truly working as a constructivist, I constantly found myself looking to identify ideas that were

universally transferable. I am conscious therefore as I look at the decision making frameworks outlined later in the thesis that there is evidence here that I am still looking for transferrable rules that are applicable to wider populations

Whilst there are differences in the way knowledge grows according to one's paradigmatic position, are there certain generalisable features about *accumulation* of knowledge? Are there common features between paradigms about the way knowledge grows? As a researcher I am interested in the role of conjecture in research. As mentioned above, a qualitative researcher will at times adopt both an idiographic approach, which respects the specificities of each case, and a hermaneutic approach, which explores the particular meanings that are produced. (Banister, Burman, et al. 1994 p2) Understanding is developed by the concept of the hermeneutic cycle and when incongruence occurs between the parts and the whole, a re-conceptualisation takes place. (Susman and Evered 1998 p95-113) These essentially inductive modes are grounded whenever possible in data. Both of these approaches and the deductive-inductive reasoning model that characterises positivist thinking have been criticised as not having the basis for significant advances in knowledge. Popper claims that significant advances in knowledge occur when the inquirer goes beyond the data and performs a conceptual leap of the imagination to consider analogies, metaphors, models, myths etc as a way to explain the data. Popper called such leaps of the imagination conjectures.(ibid)

This suggests that a balance has to be struck between the level of interpretation supported by data and conjecture that goes beyond data if real progress is to be achievable. What happens then when choice has to supported by conjecture rather than data, a point that is particularly relevant when choosing a methodology? As a researcher I notice that main reason I have chosen to enter the qualitative research world is based upon conjecture. I have no data to support the idea that qualitative research is going to be useful. Once engaged in the qualitative tradition, I have to make methodological choices that are similarly based on conjecture. I can try to make the process apparently authentic by outlining an ontological and epistemological position post hoc as I have done in the thesis. Much of what I have proposed is a retrospective analysis, some of which is based

upon experience and some of which is based upon conjecture, but this contrasts with the position I find myself at the moment of starting the research. When starting out *all* choice is based upon conjecture. So what is the status of the outcome of choice based upon conjecture? I don't know but since in every choice there is a moment where conjecture plays a part, even if it means making choices about obtaining the data to make an informed choice, one may have to resort once again to an argument based on 'usefulness'. If one's experience of conjecture as a basis for defining choice has been successful, then two things are likely to happen. Firstly, one is likely to continue utilising the method. Secondly, it might be possible to develop a skill in such a process. I already see this in the quantitative world where some individuals seem to develop an instinct for identifying research strategies that lead up blind alleys from those that do not. Some have developed a skill in successful conjecture but this skill does not appear to be subject to rational analysis and certainly not subject to any validity criteria other than past success.

In consequence, as a researcher, this whole research project has made me become aware of the high level of conjecture that I display in my propositional thinking. It is both a strength and a weakness. It encourages one to be innovative and explorative but it may also mean that the distinction between conjecture and grounded interpretation may become blurred. Even at the end of my research, I am unsure of the necessary balance between the two.

Professional knowledge

I start this discussion on professional knowledge by asking the following question: Is it possible to synthesise a working model of practice and remain adherent to the positivist paradigm? Even as positivism became increasingly sophisticated and began to recognise to what extent observational statements were theory laden, the laws of nature were seen not as inherent facts but as constructs to explain observed phenomena. Nevertheless, from the perspective of the positivist, practice and the practical knowledge generated by practice appears as a puzzling anomaly. Practical knowledge exists, but it does not fit neatly into positivist categories. (Schon 1983 p33) Positivism tried to solve the puzzle of practical knowledge by reformulating the problem as knowledge of the relationship of

means to ends. Given agreement about ends, the question, "How ought I to act?" could be reduced to a "merely instrumental question about the means best suited to achieve one's ends."(ibid) Disagreements about means could be resolved by reference to facts concerning the possible means, their relevant consequences, and the methods for comparing them with respect to the chosen ends of action. According to the positivist epistemology of practice, craft and artistry had no lasting place in rigorous practical knowledge." (ibid)

This approach emphasises problem solving and overlooks the implications of problem setting the "process by which we define the decision to be made, the ends to be achieved, the means which may be chosen." (Schon 1983 p40-41) Even when a problem has been constructed, it may escape "the categories of applied science because it presents itself as unique and unstable".(ibid) A practitioner must be able to map those categories onto features of the practice situation. Problem setting then is a process in which, interactively, "we *name* the things to which we will attend and *frame* the context in which we will attend to them." (ibid) When the paradigm conflict cannot be overlooked and there are multiple ways of framing the practice role, practitioners bound by a positivist epistemology find themselves caught in a dilemma, "this dilemma of 'rigor or relevence'." (ibid) This jeopardises the usefulness of knowledge in complex situations or when pluralist interpretations of framing are possible, for example in psychiatry.

An alternative approach is to consider practical knowledge in action and not as a sterile academic exercise. If practical knowledge is only useful in action, it suggests that knowledge should be understood and assessed in action. This approach at least pays attention to the *context* of practical action. Practical knowledge has been regarded as a form of knowledge that packages a great deal of inherent complexity economically and, whilst generalisable, permits use in a specific instance, the appropriateness of which is recognised in action.(Argyris, Putnam, et al. 1985 p233) This can be illustrated with a musical methaphor. A pianist will have acquired considerable practical skill in order to play a piano well. The skill is specific (music on a page can be accurately translated into sound) and yet can be applied to a particular piece of music, and the appropriateness of

this can be judged by reference to the musical nature, or not, in the outcome. As a pianist myself I am aware that I do not by and large see the individual notes on the page, but translate passages into a certain feeling in the hands. In this respect the action is also economic.

This suggests that professional knowledge (practical knowledge) can be regarded as a synthesis of disconfirmable (hopefully) propositions drawn from a single or multiple paradigmatic perspectives mediated through action by speech or otherwise. A methodology that proposes to research the nature of this practical knowledge should at least consider addressing the notion of 'practical' knowledge in a way that is not simply a reformulation of the problem but also pays due regard to setting. This approach suggests that a purely positivist approach would be inadequate and that an action methodology might be appropriate.

Knowledge about knowledge

Encompassing all of this is the notion that theories and research methods structure and explain the world according to their own internal logic, for they impose their own definition on the situation and also constitute what is to be considered scientific explanation. Epistemologically, the kind of understanding or knowledge arrived at may thus be no more than an artifact of theory or research method, and unrelated to the reality observed or favour a particular epistemological stance in suggesting that certain kinds of insight, understanding, and explanation may be more appropriate than others. (Morgan 1983 p150) Faced with this one is led to ask; What exactly is qualitative research? Qualitative research can be defined in a simple, but quite loose, way. It is the "interpretive study of a specified issue or problem in which the researcher is central to the sense that is made." (Banister, Burman, et al. 1994 p2) The purpose of qualitative research is an attempt to capture the sense that lies within, and structures what we say about what we do together with an exploration, elaboration and systematization of the significance of an identified phenomenon.

This suggests that the heart of qualitative research is the notion that knowledge is a debate about knowledge and implies a strategy whereby social scientists are concerned with the realisation of *possible* knowledge. After all, what is studied and what is learned are intimately connected with the mode of engagement, which influences in a fundamental way the nature of the debate. The nature of the debate includes a commitment to "methodologies, with an emphasis (at least in its pure ethnographic form) upon description rather than explanation, the representation of reality through the eyes of its participants, the importance of viewing the meaning of experience and behaviour in context." (Henwood & Pidgeon 1993 p16) So in developing the interpretive structure provided by one mode of engagement rather than by another, the social researcher directly influences what he or she will "discover" about the phenomenon being researched, realising one possible form of knowledge within a wider set of possibilities. (Morgan 1983 p367) What are the implications for this standpoint?

This suggested an important consideration to bear in mind as I developed a methodology to try and make sense of a more complex clinical situation, occasioned by paying attention to non-clinical as well as clinical processes. The research methodology must generate an understanding of how I interacted with the situation. As a researcher, I believed at the beginning that a co-operative inquiry group of doctors might provide the methodology to achieve this. I took my cue for this belief from general practice, where it is common for trainees to examine, with other doctors, a video of their clinical consultation in order to explore 'what else was happening' when patients came to see them. In this model, a key voice, that of the patient, is missing and any understandings achieved are hampered by the absence of this key actor. Part of the reconstruction of the methodology has involved identifying key assumptions I made in undertaking this work and it is clear to me in retrospect that I had paid insufficient attention to 'hearing' the voice of the patient at the onset of the research. When I realised this voice was missing, it formed the basis for changing, at a later stage, to an action science/ inquiry methodology.

Having considered what might be regarded as 'knowledge' in the clinical encounter, I proposed to consider what research question would be appropriate.

What in general terms was my area of research interest?

This question is naturally dependant upon an assumed ontological and epistemological position as a researcher. At the onset of the research, I espoused the position that the attitudes, 'medical' and more particularly non-medical, of both the patient and the doctor, were meaningful in the clinical context and themselves formed meaningful components of the wider social world. The discourse in the early part of the thesis suggests that I had reached the point where I began to take the view that the institutional components of medicine form meaningful components particularly in relation to the exercise of networks of power and control of medical knowledge. I also accepted that it was possible to know more about such meaningful components by the application of an appropriate methodology. These are all propositions that I initially accepted by suspending my scepticism at the onset of the research but which became supported by experience as my attitude towards data and data generation shifted my ontology towards constructivism. Within this assumed framework then my broad topic of research interest becomes that of non-medical processes in the doctor patient interaction.

What were, in specific terms, my research questions?

Now that the ontological and epistemological framework have been established, together with the broad topic of research interest, the scene is set to focus upon more specific research questions. Mason has identified three general types of puzzle around which to formulate research questions in qualitative research;

1. Developmental questions; how does it work?
2. Influential questions; what influence does x have on y?
3. Formulate questions to be explored rather than necessarily answered.

(Mason 1996 p15)

For each of these, I saw three sources of questions that can arise within the clinical interaction

1. Questions based around my perception of what is happening or what is not happening.
2. Questions based around the patient's perceptions of what is or what is not happening insofar as I am able to 'see' them
3. Questions that arise from this process of interacting

Within this classification a whole host of more specific research questions arose that reflect the new complexity of the clinical interaction when viewed as a constructivist rather than a positivist or post-positivist. For example; it was my perceived assumption that more than simple medical facts determine treatments. Was this assumption justified? If that was so, then what was the nature of these non-medical phenomena and what was their status with respect to medical intervention? Should a non-clinical process override a clear cut medical indication to act, for example, in the case of meningitis? What were the influences that govern the weight given to each of these processes? Where did they come from and how in specific terms did they impinge on the clinical decision making process? Who decided how this is done? How did my upbringing in the positivist tradition, and the assumptions this brought, interact with real clinical situations where was assumed that we did not behave in a positivist manner? Did I do this in any consistent fashion? If so what were the rules I had constructed for myself? Were these rules consistent? Did I have to be consistent, after all consistency was a fundamental tenet of positivism? What did I do with information from a patient that appeared to be a departure from positivist epistemological information? Did I disregard it-obviously, subtly, covertly, manipulatively? If I used it, what were the 'rules' that governed this strategy? Did I construct situations that prevented such information from emerging? How was this given voice in the first place? How could this be done better? Was that necessarily appropriate? What was the influence of institutions, such as hospitals, medical institutions such as the General Medical Council, folklore in allowing such information to be presented as epistemologically valid in the eyes of the medical profession? Such questions go on and on. As a researcher I noticed that adoption of a

constructivist ontology not only raised complexity and immediately raised the level of inquiry but it also obliged me to face another issue; the issue of complexity versus clarity.

In general terms one is faced with two choices. On the one hand I could confine myself to an in depth analysis of one or two of these questions. For example, How did I manage information from a patient that appeared to be a departure from positivist epistemological information? This approach might have partly overcome the problem of complexity and offered an analysis that had greater clarity but still left me with the problem of precisely which question to ask. On the other hand it was possible to address a list of coherent questions that would attempted a broad canvass of the whole subject but which might have, in the final analysis, attracted the criticism of superficiality.

As a researcher I also noticed how easy it was to generate a large number of questions and this consideration led me to start asking questions about the nature of questions themselves. What were good questions, what made a poor question? What was an empirically useful question, what kind of questions increased understanding but had no utility? When was it appropriate to ask questions and when was it inappropriate? Given that this research was taking place during a clinical consultation, then the specific intellectual puzzle become:

How did I formulate *relevant* questions *in the moment*?

Of course hidden within these questions are a raft of other subsidiary questions many of which concern themselves particularly with validity criteria such; How is it possible to know that this was being done in a reflexive manner? Nevertheless the idea of focussing attention onto the nature of relevant questions in the moment fitted in with the notion of raising my level of inquiry in this area generally and was also in keeping with a conceptual model that included a level of asking questions as a researcher. The 'constructivist' or 'reflective practitioner' was asking questions of the 'positivist' and the 'researcher' was asking questions of them both.

Section 2

Linking research questions, epistemology and methods

The first section 'Ontological and epistemological issues in relation to a research question' has considered what constituted data in my chosen qualitative research field and explored possible research questions. In this second section, according to the overall scheme of

1. Ontological and epistemological issues in relation to a research question
2. Linking research questions, epistemology and methods
3. Ethics, morality and politics of the research process
4. Producing a practical research design

I looked at ways of linking such data with the various methodologies available to developing understandings about what was happening.

What sources of data and methods of data generation are available?

I started by considering all the possible sources of data and general methods of data generation. It is hardly surprising that hospital environments are data rich for a study of this sort. For in addition to the obvious source, the doctor/ patient interaction in the clinic, there are a variety of other sources that might provide useful insights and understandings of what is happening. Furthermore, most people have at one time or another been a patient and this extends the potential sources of data almost limitlessly. The principle sources for this study were the following.

Hospital clinics.
My colleagues.
My colleagues at work in a multidisciplinary clinic.
My family.
Discussions with friends, medical and non medical.

From these data sources, data could be generated in the following manner with varying degrees of systematic methodological approach and rigor.

My own reflective practice.

Short informal interviews in the clinic.

In depth interviews with patients.

Others watching me in the clinic e.g. medical students, other doctors.

My colleagues at work in the form of a discussion group.

Postgraduate research group at Bath.

The literature; medical and organisational.

My supervision sessions.

The examination process.

To underline the variety of data available, Mason has recently listed some of the possible sources of data.

People, social actors,
Bodies, subjects, objects,
Minds psyches,
Rationality, emotion, thought, feeling memory, senses,
Consciousness, subconsciousness, instincts,
Understandings, interpretations, motivations, ideas,
Attitudes, beliefs, views,
Identity, essence, being,
Self, individuals,
Others, collectivities,
Representations, cultural or social constructions,
Experiences, accounts,
Stories, narratives, biographies, evolution, development, progress,
Texts, discourses,
Words, codes, communications, languages,
Actions, reactions, behaviours, events,
Interactions, situations, social relations,
Social or cultural practices,
Social processes,
Rules, morality, belief systems,
Institutions, structures, the 'material' market,
Cultures, societies, groups, producers, consumers,
Nature, genes, humans, animals,
Empirical patterns, regularities, order, organisation, connectedness,
Empirical haphazardness, spontaneity, disorder, disorganisation, chaos and disconnectedness,
Underlying mechanisms,
One objective reality, multiple realities or versions,
(Mason 1996 p11-12)

The use of and interpretation of such data of course reflected the basis of one's ontological positioning in the world, however, the choice was enormous and I was approaching this research without any strong theory to handle this data. Consequently, I was faced with the problem of making sense of vast amounts of data. The presence of such large amounts of data suggested the development of a mental open-ended indexing system "to allow an array of concepts and categories to emerge from systematic inspection of the data corpus." (Henwood & Pidgeon 1993 p21) In conventional grounded theory this is undertaken in a more systematic manner, but I proposed that the process was helped by considering a variety of sources of data and data generation to generate and challenge interpretations. This then suggested the general proposition that a significant departure from the general formula of one on one researcher interpretation (doctor interpreting what happens in the clinic independently) would be an important feature in developing understandings. This indicated the need to obtain interpretations from others, either singly from other observers in the clinic, or from an inquiry group. This approach, where data is collated from different sources and used to increase understandings of social reality, is called data triangulation.

Triangulation, essentially the use of different vantage points, takes a variety of forms. Triangulation can take the form of data, investigator, method and theoretical triangulation (Banister, Burman, et al. 1994 p142-159) and time, space and validity triangulation. (Cohen & Manion 1989 p269-286) Since the clinical consultation took place usually between the patient and myself, and no other people were directly involved, it made it more difficult to generate opportunities for triangulation. Consequently, it seemed important to generate as many opportunities for triangulation as possible for the study to remain credible.

There are opportunities for data triangulation in a number of ways. Firstly, each clinic provides an opportunity to collect data from different participants both from my perspective and from theirs by asking appropriate questions. This is by far the most important source of data in this research. I do approximately three thousand consultations

per year, so that during the course of the study I have made approximately 15,000 consultations. Many of these are multiple consultations on the same patient. To supplement this, it was also possible to conduct in depth interviews and subsequent exchange of transcripts with a few patients to specifically explore areas of mutual interest. This process obviously provides an opportunity to question and begin to validate some of the interpretations that are made during the course of the shorter consultations (average time seven minutes) that are typical of a normal clinic. This was supplemented by making video recordings of consultations to review at length, showing them to other researchers from non-medical disciplines in order to generate interpretations and data to increase the variety of perspectives.

In order to address the criticism that any finding or interpretation may be an artefact of the method of data generation, different methods of generating data should be also be sought. Hospital life gave me many opportunities to collect this in number of different ways. The postgraduate research group of postgraduate researchers, the hospital group and my own doctor/patient group were all discussion groups that generated data and interpretation about the clinical process and offered a degree of method triangulation. These individual groups will be described in detail later in this section.

Finally, theoretical triangulation embraces multi-theories and "breaks through the parameters and limitations that inevitably frame an explanation that relies on one theory. It recognises complexity and diversity and that multiple realities exists....Research which tests competing theories will normally call for a wider range of research techniques than has historically been the case; this virtually assures more confidence in the data analysis." (Banister, Burman, et al. 1994 p145-149) One is looking in the final analysis for different theoretical perspectives to shed light upon the situation and this would be in keeping with my conceptual model of positivism, constructivism and paradigm perspective outlined at the beginning of this thesis.

This description of triangulation overlooks three other technique of triangulation that became empirically useful during the course of the research. At first sight they might

appear to be procedures for self-referencing but I would like to make an argument for their serious inclusion as alternative forms of triangulation. I have termed these 'experience', 'paradigmatic' and 'behaviour' triangulation.

When I had started the research, I had been qualified as a doctor for fourteen years. An approximate calculation indicates that I must have seen in excess of 15,000 patients over that time. This represents a body of experience (assumptions as well!) that manifests itself in certain patterns of behaviour, attitudes and interpretations, principally on my part and possibly on the part of patients. I would like to argue that if one then introduces a change in practice, then there is a considerable body of previous experience to which one can appeal as a perspective on any change. It is this body of experience that I term 'experience' triangulation. This body of experience is to my way of thinking an empirical, utilitarian body of evidence based on perceived usefulness. It will be the distillation of many learning encounters, some of which appear to have worked and were adopted as changes in practice, others of which did not work and were abandoned. Any new interpretation or action generated by another perspective can be assessed with reference to this body of evidence. Furthermore, in the final analysis, as a practising surgeon, the argument of 'usefulness' is one that I cannot afford to overlook and I do not believe that only a constructivist epistemology would generate interpretations that are 'useful'. This statement on 'usefulness' suggests that the definition of 'useful' is universal and straightforward and of course it is not. Who defines usefulness, the doctor or the patient, and against what criteria and values? My whole approach to this thesis was centred around my concerns about 'usefulness' as a doctor and this research was an attempt to be more useful in ways that are not judged solely by the doctor. Later in the methodology section, I try to address the question of 'usefulness' when discussing validating my change in practice with a set of twelve validity criteria I perceived as authentic.

The process of shifting from an espoused positivist or post-positivist framework represents a paradigmatic shift. If one continues to look at the 'same' data but through different paradigms then this can be conceived as another form of triangulation. This is

what I perceive as 'paradigmatic' triangulation. A constructivist would argue that positivism is one possible perspective in a constructivists world view but I have argued elsewhere that it is possible to 'play the game' and be both a positivist and a constructivist so that this does represent a true paradigmatic shift. The alternative argument is that the 'data' is not the same, because an immutable principle of constructivism is that no two sets of data can ever be the same. I would argue that at one level, the level of process, the data is the same. Every patient coming through the clinic is engaged, at an archetypal level, in a medical process that may have for example 'healing' as its intended purpose. Of course each patient's espoused agenda, each patient's context, is entirely different, but at the level of purpose there may be similarity. This level of purpose can be triangulated through the use of different paradigmatic perspectives.

Finally, what do I mean by 'behaviour' triangulation? The hospital and the medical organisations within it represent a structure whose origins arise from an espoused positivist stance on medical knowledge. It means that as I sit in my clinic adopting a constructivist stance, I am surrounded by an organisational network, which implicitly questions this approach and constantly reminds me of what is perceived as the most 'appropriate' way to behave in a clinic. I notice this especially when I come to teach the trainees, who by and large expect to be engaged within a positivist framework. When I teach trainees, I feel perceived as *the* expert, an institutionally empowered expert. This flip-flopping between a reference behaviour that is institutionally acceptable and my own behaviour in the clinic, which may be different, I see as a form of behaviour triangulation. As a researcher it constantly reminds me of alternative perspectives.

Can I answer the charge that each of the additional methods of triangulation cannot be justified on the grounds that interpretation is made with reference only to oneself? I would argue that no matter what form of triangulation, be it data, method, investigator or theoretical, there comes a point where the interpretation offered by other viewpoints has to be re-interpreted with reference to oneself. I can choose to accept or reject the interpretation offered by one of the other members of the postgraduate research group or occupy an intermediate position and accept part of the interpretation. This may manifest

itself in what I choose to put in the thesis and what I choose to exclude. Even if I do this with considerable reflexivity, there is still a point when I make a choice as the principle owner of this work about whether I wish to accept an interpretation or not. My position is one based upon what I perceive as authentic behaviour or not. Instead of answering the critique that 'experience', 'paradigmatic' and 'behavioural' forms of triangulation are illusory, let me ask the question; what happens if I choose to ignore such viewpoints? I would argue that I am failing to address a body of 'evidence' that may represent interpretive bias and that failure to do so is inconsistent with authentic reflexivity.

Finally, the list of possible data sources produced at the beginning of the section needs to be reduced to manageable proportions. Given the ontological and epistemological perspectives that have emerged so far, emphasis would need to be given to the following;

People, social actors,
Rationality, emotion, thought,
Consciousness, subconsciousness, instincts,
Understandings, interpretations, motivations, ideas,
Attitudes, beliefs,
Institutional constructions,
Experiences, accounts,
Actions, reactions, behaviours, events,
Interactions,
Social or cultural practices,
Groups,
Underlying mechanisms,
Multiple realities or versions,

I have particularly highlighted the role of groups because of a perceived need to pay attention to the level of unsubstantiated interpretation. An interpretive group might serve to limit the level of uncritical 'conjecture' by challenging it and slowing down the process.

What methodologies are available?

A key theoretical problem underlying my research into clinical practice was to try and establish a relationship between the quantitative and qualitative approaches. This means that as well as a review of what constitutes 'data', it is necessary to review the methodologies that generate data in each paradigm. It is on the basis of understanding this that I make claims as a researcher to have an awareness of paradigm. Consequently, this review of methodologies is rather long but I see it as an important piece of evidence to support this third conceptual level of awareness of paradigm.

There are two specific problems to consider when discussing the various methodologies available. Firstly, what is my paradigmatic perspective in the first place, so that the choice of methodology is coherent with this and with the nature of the data. Secondly, how is the choice of methodology to be made, given that there are often alternatives even within a single paradigm.

The perspective offered by any qualitative researcher on any methodology arises from a paradigmatic position itself. For example, from the perspective of the constructivist, the methodology of positivism is seen as "experimental and manipulative", (Guba & Lincoln 1994 p110) a position that a positivist would not necessarily accept. During the course of the research, I became more conscious of the theory and value driven nature of data and in the process shifted towards critical theory and constructivist paradigms. My view of methodologies portrayed here then is overtly from the perspective of a constructivist. However, as a researcher, I acknowledge that each paradigm is a coagulation of agreed assumptions that serve the purpose of making data within that paradigm researchable. I, therefore, explicitly acknowledge that any analysis made here is made with an awareness that this can only be from a particular paradigmatic stance and is of course limited by that.

As to the problem of variety of methodology, I cannot hope to, nor see the value of, a careful review of every single published methodology in the qualitative tradition. For

example there are now more than thirty varieties of action inquiry model that have so far been described. I have chosen to handle this review with what I see as purposive choice and selected from within each of the five main paradigms representative examples from the main schools of qualitative methodologies. This is not completely straightforward. It is generally now agreed that the distinction between each of the qualitative paradigms is becoming blurred and especially between critical theory and constructivist. It is becoming more difficult to attribute each methodology to a strict paradigmatic position. It should also be acknowledged that the same methods can be applied in different paradigms. With these points in mind, What are the key features underlying the methodologies within each paradigm?

The postpositivist approach places an emphasis on "'critical multiplism', (a refurbished version of triangulation) as a way of falsifying hypotheses." A methodological requirement is that inquiry takes place in "natural settings and data is collected situationally." Discovery is considered as an important element in the inquiry process and viewpoints are "collated to determine meanings." (Guba & Lincoln 1994 p110) The critical theorist sees data as arising principally from dialogue. The dialogue should be dialectical in nature with an emphasis on "informing ignorance and minimising apprehension." The constructivist maintains the interactive nature of gathering data but places emphasis on the fact that that "construction can only be elicited by and is a process of such interaction." The aim is to collect a consensus construction by a process of "distillation" that is both more informed and sophisticated.(ibid) The collaborative action inquirer emphasises the importance of democracy in research and one model maintains that this collaboration commences at the point of formulating research questions, continues into choice of methodology and thereafter. The distinction between researcher and researched is minimised, even to the point of being absent. The conceptual image is of conscious research 'cycling'. The use of the methodology in this way illuminates the world of each participant's "practice (practical knowing), which leads to new forms of encounter (experiential knowing), which find ways to represent this experience in significant patterns (presentational knowing) and which feeds into a revised propositional understanding of the originating question." (Heron & Reason 1997 p283)

With this general background in mind, I propose to consider the following methodologies:

Observation
Surveys
Interviewing
Discourse analysis
Personal construct approaches
Experiments and quasi experiments
Ethnography
Various forms of action research
Co-operative inquiry

Although each of these methodologies were considered at or close to the onset of the research, the reconstruction made possible by the resubmission of the thesis has allowed me to reconsider the part played by each of these methodologies in my research. In portraying these methodologies, I have also taken the opportunity to show how they were incorporated into my research and, where possible, show how they were related to my practice. Each methodology described begins with a general description of the methods and leads onto a discussion of aspects of the method I found useful, together with some of the difficulties I encountered, during the research.

Observation

For every methodology, observation is a key feature but what characterises observation as a methodology in it's own right is the separation of researcher and researched. There are a number of points to consider when contemplating observation as a methodology.

Structuring; this may range from being highly structured and detailed to diffuse unstructured observation.
Focus; this may take the form of narrow concentration onto specific aspects e.g. single non-verbal clue to broad focus.
Knowledge; Do those being observed have knowledge of the research process?

Explanations; given to those being observed, which may be 'full' to none.
Time scale; one-off to extended observations over a period of time.
Methods used; note taking, audio, video recorders, checklists, etc
Feedback; given to the observed from full sharing of observations and interpretations to no contact with participants at all.

In attempting to validate the knowledge gained in this way it is considered important to develop a clear "audit trail" which includes:

Describing the context, including physical setting, date, time, weather etc.,
Describing the participants. Who they are, with attention to age, gender, ethnicity, clothing, physical description.
Describing who the observer is, including any prior links with the observed,
Describing the actions, including verbal and non verbal clues,
Interpreting the situation by attempting to give an indication of it's meaning to the participants and to the observer. This means making as clear as possible the evidential basis for the interpretations. In the process of doing so it may be difficult to identify one's own projections.
Considering alternative interpretations of the situation and giving reasons. How would it look from another perspective e.g. child, behaviourist etc.
Exploring your feelings in being an observer including your experience of the observation. What is very useful here is to notice what is left out in the first analysis, which may be seen to reflect natural bias in the observer. (Cohen & Manion 1989 p129)

The emphasis in observation as a methodology is on the researcher acting as an outsider so that in this respect observation has been criticised as "very much 'objectivist' in it's standpoint, with the researcher sometimes using the material gained very much for her or his own ends." (Banister, Burman, et al. 1994 p19) I became aware of this objection on one occasion during a discussion in the hospital inquiry group. One participant had spent the whole time observing the group and recording who had looked at who. Just as the group discussion was finishing, he announced what he had been doing and showed

everyone the finished diagram. The response varied from mild amusement to quite overt irritation. On this occasion there had been an opportunity for the 'researched' to give some feedback to the researcher and this may have been the reason why the exercise, or anything like it, was never repeated.

There may be a role for observational techniques as part of a methodology, which I will discuss later, but the main methodological concern is centred on trying to observe *and* participate at the same time. When I am taking a clinic, for most of the time there are no other participants other than the patient and myself; there is no third party undertaking an observational study. To consider straightforward 'observation' as the sole research methodology, I would have to consider carefully the question of acting as both 'observer' and interpreter in a situation in which I am also a participant. I am obliged to ask the question is this possible and even if it is, is this desirable?

Accounts that typically emerge from participant observations are often described as subjective, biased, impressionistic and idiosyncratic. Not only are they criticised in terms of genuinely advancing understanding, they are also criticised as lacking precise, quantifiable measures that are the hallmark of survey research and experimentation. Such impressionistic interpretations are referred to at an extreme as 'going native' (I note the cultural superiority implied by the term 'native') as a result of role playing within such a group. (Cohen & Manion 1989 p129) It could be argued that someone in my position would be commencing a research study having 'gone native' from the onset and is being asked to disengage from one's cultural and historical perspective from the position of one's own cultural and historical perspective i.e. no other reference point. "How do we know that the observer does not lose his perspective and become blind to the peculiarities that he is supposed to be investigating?" (ibid)

As a researcher this raises significant problems of external as well as internal validity. External validity is an assessment of the applicability of one piece of research to other situations, which is in turn dependent upon internal validity, an assessment that the findings represent an adequate representation of the phenomenon (within paradigmatic

assumptions). Arguments have been already put forward suggesting a relationship between data, theory and values so that data and explanation would appear to be 'theory and value' mediated. It suggests that reliance upon observational techniques may produce a perceived reality that is structured through the very framework being utilised. (Banister, Burman, et al. 1994 p30) Furthermore, at the heart of observation is the assumption that people try to make sense of the world and act in a manner that is always purposive. Our everyday experience suggests that this may be true most of the time and that we do follow implicitly a set of social rules and conventions that influence our behaviour and appear to give it purpose. The methodology of observation does not contain a structure that can challenge this assumption.

Nevertheless, throughout the research, I was observing both myself and others and it became a methodology that I found important. To try and address some of the problems in generating data solely through my own observations, I looked for opportunities to use observation of the clinical process in other ways. There were occasions when medical students, colleagues, nurses and relatives of the patient were present in the clinic. Such participants were not 'directly' involved in the clinical process and formed a cohort who could to some degree act as 'observers'. Insights gleaned in this way could initiate moments of 'conjecture' that seemed to lead to understandings. For example, a medical student once made a comment about the degree of eye contact I was making with patients and commented that it was like watching a "born again Christian". This observation made me think about eye contact in general and so I started to ask questions such as 'What determines whether I increase or decrease the level of eye contact?' This meant that I started asking patients about eye contact. I learnt from a number of patients that the presence of a computer in the room of many of their general practitioners had reduced the level of doctor/ patient eye contact. This was perceived as a reduction in medical interest in their problem and interpreted by them as an increase in interest in the cost of their problem.

Other forms of observation included showing videos of clinics to other members of the postgraduate research group, who would observe and interpret what was happening.

Although interpretations were made by members of the research group, no attempt was made to validate any interpretation with the patient so that I would accept that there is still a problem of checking inference with data. In response to this I would argue that the emphasis in the video analysis was largely on my own behaviour and the group would offer interpretations of my interpretations as part of a process to try and increase my reflexivity. The observations and interpretations' they made served as a source of conjecture and reinterpretation, which could on occasions be shown to have an 'audit trail' to significant change. For example, it was commented that I would sometimes start to examine someone without asking permission. I would lean across and start to look into an ear and to an outsider this looked like an invasion of 'body space'. Afterwards, I became very aware just how often I was doing this and so instead would always ask permission before taking such action. This was extended to noticing that I would then perform procedures without seeking further permission, for example cleaning out an ear, so that part of the process of seeking permission for intervention involved explaining what all the equipment was and what I was proposing to do and why. These changes were extended further when, in my capacity as a teacher in the department, I raise this issue when discussing patient examination. Eventually it led to considering how clinical space was managed so that the presence of equipment in a room was an expression of medical power. Observation in this was became useful as a mode of 'conjecture' that led to change.

Surveys

In this review on survey methodology, I have chosen to exclude interviewing methodologies, which I have considered separately as it is central to the doctor patient interaction. Surveys as a methodological technique are already familiar to me in positivist research, especially in the field of retrospective medical note analysis. In qualitative research, surveys have been defined as methods of gathering data at a particular point in time with the intention of;

"(a) describing the nature of existing conditions, or

(b) identifying standards against which existing conditions can be compared, or
(c) determining the relationships that exist between specific events, which vary from those that provide simple frequency counts to those which present relational analysis." (Cohen & Manion 1989 p97)

This can be done in a variety of ways such as structured or semi-structured interviews, self-completion or postal questionnaires, standardised tests of attainment or performance and attitude scales. With the exception of interview data, the data generated by survey methodology would, it seems to me, to be essentially epistemologically post-positivist or attempting to be positivist. The general intention is to handle the data by a process of quantification after which an attempt is made to tease out simple relationships between factors deemed to have some bearing on the phenomena in question. For example, correlational techniques are intended to answer three questions about two variables or sets of data.:

(a) Is there a relationship between the two variables or sets of data? If the answer is 'yes', then two questions follow:
(b) What is the direction of the relationship? and What is the magnitude of that relationship (Cohen & Manion 1989 p154-157)

In the 'Conclusions' section, I draw attention to the considerable proportion of qualitative research in the medical literature that is dependant upon this approach. The argument in favour of such research is that there may be a need to "discover or clarify relationships and where correlation coefficients will achieve these ends. It is especially useful in the initial stages of a project and may become a source of hypotheses or when the objective or one set of objectives, is to achieve some degree of prediction." (Cohen & Manion 1989 p164-165). Prediction studies may be considered suitable where a group as opposed to an individual is the focus of a project but in which case a firm knowledge base is present

My particular interest in engaging in qualitative research was to further my understanding of a situation inductively. The essentially deductive approach of data gathering and hypothesis generation that characterises survey did not offer sufficient difference of approach to suggest that this methodology would be especially useful. Its essentially postpositivist position still paid lip service to the standards set by positivism and failed, it seemed to me, to get at the meanings embedded in action, at the logic of action.(Argyris, Putnam, et al. 1985 p20) It didn't seem to have the methodological basis to explore action and practice. For this it seemed to be necessary to have a methodology that was usable *in the moment* and whilst retrospective research is powerful and helpful it is still retrospective. As a researcher I appreciate that in one sense, analysis of outcome in all research is retrospective, from astronomy to participative research. But I would argue that in certain methodologies the emphasis may be different so that some are more retrospectively orientated than others. I was looking for a methodology that asked What if I do this *now* as a test of a position, what is the outcome? This needs to be coupled with a level of inquiry that enables exploration to be conducted there and then. A survey methodology obviously does not offer such opportunities.

Finally, there is a low level of participation by the actors involved. This commences in the formulation of the research question, the method of analysis, interpretation and sense making of the responses and what happens to the data afterwards. My experience of surveys in the positivist arena had already taught me that to include a significant level of participation on the part of patients was going to be much more difficult even when overtly espousing a constructivist stance. Last of all, but important at a personal level as a researcher, after fifteen years, I was bored with doing, and supervising surveys.

Interviewing

The interview is important to consider because it represents an extension of what I am already doing in the clinic. Interviews, a special form of survey, has been defined as "a two person conversation initiated by the interviewer for the specific purpose of obtaining

research-relevant information, and focused by him on content specified by research objectives of systematic description, prediction or explanation." (Cohen & Manion 1989 p307-308) Not all qualitative researchers would agree with this definition of a research interview with its emphasis on detachment and distance between researcher and researched and some might argue that such emphasis on separation of researcher and researched may be "rudely challenged by the face-to-face interview." (Banister, Burman, et al. 1994 p49)

An interview is an important part of many methodological approaches but what is expected from an interview might depend on the different ontological positions of the researcher and the reasons for conducting interviews. A more positivist or post-positivist researcher might expect to;

1.Measure what a person knows (knowledge or information), what a person likes or dislikes (values and preferences), and what a person thinks (attitudes and beliefs).
2. Test hypotheses or to suggest new ones; or as an explanatory device to help identify variables and relationships. (Cohen & Manion 1989 p318)

Such a perspective might also be reflected in the approach to bias. One position is to regard the interview as 'pure information transfer' in which the process from the perception of the researcher is characterised by accurate data with bias largely eliminated. A second conception recognises the inevitable place of bias and attempts to 'recognise and control it' by conducting interviews with a range of interviewers with different biases. These approaches to bias "regard the inherent features of interpersonal transactions as if they were obstacles to sound research and therefore to be removed, controlled or at least harnessed in some way." (ibid)

A constructivist or participatory researcher might adopt a different approach and use such 'interpersonal transactions' in interviews to illuminate:

1.Subjective meanings rather than eliciting responses.

2.Exploration of issues that may be too complex to explore through quantitative means.
3. Salutatory lessons in research involvement and practice.
4. Power relationships. (Banister, Burman, et al. 1994 p50-51)

The approach is to consider the interview as an encounter necessarily sharing many of the features of everyday life. This position takes the view that there are features of all interviews that are unavoidable and should not necessarily be regarded as problems. An interpretation attempts to generate a "theory of everyday life that takes account of the relevant features of interviews." (Cohen & Manion 1989 p311-312)

A number of factors shape this approach. The first one is the level of structure in the interview. A highly structured interview, with questions that encourage short, even yes/no answers, allows virtually no opportunity for the interviewee to exert control on agendas and areas of interest. Interesting and unexpected lines of exploration may be overlooked. A loosely structured interview would implicitly and explicitly acknowledge that research is set up and conducted within power relationships that are identified, acknowledged and negotiated by both interviewer and interviewee at the onset and as the interview progresses. Such an approach acknowledges that participants hold and use their positions within the research relationship. Such an approach might empower the interviewee, who is neither passive nor unknowing about their positioning and who may use this to achieve specific outcomes within the interview. As an interviewer one is then forced to confront one's own participation within the research and a change in participation may be reflected in the move from designating the people "who form the focus of research as 'subjects' to 'interviewees' or 'participants' or 'informants' or 'co-researchers'." This emphasises the fact that research is set up within power relationships. (Banister, Burman, et al. 1994 p52-53)

With this in mind, Bannister (ibid) has identified four general approaches that inform interviewing practice in qualitative research. These different approaches reflect different ontological perspectives and are described as;

ethnographic,
'new paradigm',
feminist and
postmodernist.

In an ethnographic approach there is a clear role of demarcation between researcher and researched in determining the research topic and outcome. In 'new paradigm' research, the relationships are viewed as a collaborative enterprise involving "full participation of the interviewees as the researcher strives to carry out research in a non-exploitative, non-dehumanizing way." (Reason and Rowan 1981) In feminist research issues of power are placed central to the research. Finally, postmodernist approaches might include social constructionist or narrative approaches which questions the presumptions that participants within research share the same research goals. "Research is subordinated to a preconceived or more or less imposed interpretive framework, which may not be of immediate benefit to the informant at whose expense careers are advanced." (ibid)

This raises the whole question of assumptions that structure all research. In interviews there is a chance to recognise these assumptions both beforehand, in the moment and afterwards. Beforehand, by planning and articulating such starting assumptions; in the moment during the interview by developing an approach that encourages one to question assumptions that become apparent as part of an interviewing process; and afterwards as a reflective practice. By raising one's level of attention to the many assumptions that underlie research it encourages an attempt to theorise the impact of such assumptions upon the research process. Such an awareness 'demands great reflexivity'. (ibid)

In developing such reflexive analysis, Bannister identified a number of points to consider. These included recording what's lost (and gained), which particularly relates to written transcriptions, and taking care not to over-interpret, including manipulation to produce meaning that isn't there. A thematic interpretation from one person alone may undermine credibility so that the reactions of other participants to interpretations is regarded as important. This may result in multiple readings that may make overall interpretation very

cumbersome so that one becomes stuck in the "quagmire of relativistic nihilism, which disempowers us from using the research to say anything." For this reason it is useful to try and separate out readings from intentions, which might include an analysis of the researcher's own motives in presenting any material. Some researchers may have privileged access so that the issue of exploitation needs to be addressed and finally, there is the danger of "fetishing particular strategies" by selection and interpretation of material. (Banister, Burman, et al. 1994 p63-67)

Such awareness in interviewing has considerable significance as a researcher in a medical clinic. The medical interview that takes place between a doctor and a patient is highly structured already. It is used principally to obtain medical information that is used within a positivist paradigm. "What colour was the discharge from the ear?", "Did you measure your temperature during the episode of fever?". If at the same time as a doctor one is trying to develop a practice that is more reflective, that is more constructivist in ontology, such a structured 'medical' interview forces one to confront one's own participation within this process. To what extent does a highly structured medical interview disempower the interviewee? Is this appropriate? At the same time one is asking, as a researcher, What ontological position am I adopting here? Is it positivist, post-positivist, constructivist or even participatory? Whatever ontological position I perceive myself to be adopting, Am I using an appropriate model of interviewing?

Such a complex interplay between the highly structured medical interview and the more constructivist approach to interviews that was developed as a reflective practitioner and researcher, suggested that it may be necessary to conduct separate interviews *about* the medical interaction. In this way the whole process of being in a clinic, being in a hospital, considering different forms of treatment could be examined in detail and the medical 'problem' could to be put aside for a moment. This approach made sense to me so three extensive interviews were made with David, Patrick and Valerie (Appendices 1,2 &3).

There are a number of ways in which selecting interviewees/ participants can be undertaken and they have been divided into probability and non-probability based methods;

Probability based

1. *Simple random* sampling. Selected using some random number selection. Everyone has an equal chance. The complete list of the population is needed before sampling can take place.
2. *Systematic* sampling. Involves sampling in a systematic fashion e.g. every 20th case
3. *Stratified* sampling. Dividing the population into groups then subjecting the groups to random sampling.
4. *Cluster* sampling. Randomly selecting from a cluster that may present largely through convenience or some other reason.
5. *Stage* sampling. An extension of cluster sampling in which samples are taken from samples in a systematic fashion.

Non probability based

6. *Convenience* (or accidental) sampling. Usually captive audiences.
7. *Quota* sampling. Attempting to obtain representatives of the various elements of the total population in the proportion in which they occur.
8. *Purposive* sampling. Handpicking of cases on the basis of judgement.
9. *Dimensional* sampling. Extension of quota sampling. Involves identifying certain factors of interest and obtaining at least one respondant for each of these interests.
10. *Snowball* sampling. A small number are indentified with the characteristics of interest and these are then used to identify others.

(Cohen & Manion 1989 p97-123)

At one level my method of sampling to obtain these three extensive interviews is potentially a difficult area to justify and at one level it is not. I would argue that my selection was 'purposive' sampling but this immediately raises the question "Whose purpose? My (the researcher's) purpose?" This question involves an analysis that is at

least partly linked to the ethical position of being a researcher. In the process of 'purposive' sampling such choices may be based upon convenience, lack of expected dissension from the interviewee and exploitation on my part. I have chosen to present interviews from three individuals for a number of contrasting reasons and these reasons represent an opportunity to look at some of the differences such contrasting views generate. I knew all three interviewees well because I had either looked after them as patients for a number of years (David and Patrick) or known them as a friend (Valerie). The first interviewee (appendix 1), a businessman my age, had a particularly difficult treatment choice that interested me and who appeared to discount a positivist analysis in deciding what to do. The interview is fairly structured. The second interviewee (appendix 2), older than myself, had a scientific background, and seemed to adopt a more positivist approach to problem solving. This was an assumption I agree but I would argue that an espoused positivist approach from a patient might represent a different ontological view from the first patient. The interview is semi structured in nature. Finally the third patient (appendix 3), a woman about my age, faced a decision that was similar to the other two but might have a perspective as a woman that would have significance for me as a male researcher. She was the only one who had not been looked after by me as her doctor. The interview was unstructured other than a broad statement on my part about the nature of my research and my interest in hearing her story in detail. There are many other variables that one could be justified in including e.g. race, class, childhood attitudes, different interviewers, but the interviews are presented in this thesis mainly as an example of the kind of reflexive interview I was trying to develop.

The other form of interview was the 'medical interview' of the clinical consultation and approximately 15,000 were conducted during the period of the research. These form the basis for much of the interpretation found in this thesis. Such moments when understandings emerged, usually appeared as a surprise. Cohen does not include a category of 'surprise' sampling. If my judgement (and in this respect sampling was purposive) suggested that something interesting was happening in the consultation, then a moment might be taken to explore this. For example, if a patient talked about 'instinct' or

'instincts' or 'gut feel' or started to use the word 'feel' rather than 'think' in relation to deciding what to do, then I might take the opportunity to inquire about this in more detail.

Personal construct approaches

When I was considering a methodology to explore decision making, I was made aware of personal construct methodology by a colleague. We were exploring the possibility of using this methodology in relation to some other research work and as a consequence I considered whether or not it might play a role in my PhD research.

Personal construct approaches developed from the work of George Kelly in 1955, who took as his starting point the assertion that;

"objective reality is a myth. Our subjective reality is based on the meanings we have attached to previous experiences. It is the *meaning* that is influential, not the event itself." p73. (Banister, Burman, et al. 1994 p72-91)

In our relationships with others "we are constantly searching for meaning and apply our own personal theories in an attempt to understand what is happening. We constantly restructure our frameworks, understandings and meanings to increasingly develop a world that operates in a way that is useful to us" (ibid) and results in more effective communication and interaction with others. It is essentially a dynamic search for personal understanding gained by recognising similarities and differences in our experiences. (ibid)

Personal construct approaches are developed on the basis that "our personal frameworks, or construct systems, are made up of a vast collection of similarity-difference dimensions or bipolar constructs. We each uniquely yet systematically hierarchically network our constructs" (ibid) These bipolar constructs may be may be "logically or idiosyncratically opposite. In this way our current construct system frames our reality, aspects of which will be clear and appropriate whilst others remain unclear or incompletely described."

(ibid) Its ontological perspective will be constructivist because the method implicitly acknowledges that there are alternative ways of viewing the same situation, which are judged only in terms of their usefulness and not as elements of an absolute truth. Each of these viewpoints is acknowledged as a valid construction, so this approach recognises the richness, relevance and complexity of personal experience.

This methodology calls for a considerable degree of reflexivity on the part of the researcher in order to engage with the participants in a collaborative manner, with a degree of mutuality to try and gain an understanding of the participant's reality. The completed research is a more or less useful construction, which is, of course, "open to reconstruction." The whole approach "encourages the democratisation of the process of research. The subjectivity of both researcher and researched is embraced. People are dealt with as complex beings rather than reduced to isolated variables. Participants constructions are valued, not seen as requiring modification and adjustment to fit more easily into another's framework." (ibid)

One method of developing such constructs has been through the use of repertory grids. Although they have been mostly used quantitatively, some have advocated that they can be used qualitatively. The approach involves a number of stages:

1 Choose a topic of concern, which has the potential to offer insight. e.g. relationships with doctors.
2. The participant chooses an appropriate range of elements or roles e.g. various experiences with the different doctors or healthcare workers they have had in their lives. These include doctors they have liked as well as disliked, communicated well with or otherwise etc.
3. A grid is then constructed using contrasting qualities e.g. Clear communicator-rambling, good negotiator-directive, weak-strong, etc.
4. The individuals are then scored according to whether they were more like one end of the scale.

An attempt is then made to look for patterns, e.g. a clear doctor may be a directive one; a powerful doctor may be a clear one. A more participative approach involved exchanging the grids for others to complete, so called 'exchange grids', where both participants and researcher set up the grids together and fill them in before exchanging them with one another e.g. a doctor with a patient. (Thomas, L.F. 1979) These grids can form the basis for further grids.

Other personal construct methods may involve either 'self characterisation', in which the participant is invited to "write a character sketch of themselves" from say the point of view of a close friend; language can be entirely replaced by, for example, the use of drawings. These are used to assess how the person construes and are analysed co-operatively with the researcher. (Banister, Burman, et al. 1994 p72-91) Bannister feels that this methodological approach may make it very difficult, perhaps impossible, to break out from our own constructions. Apart from implicitly accepting the 'truthfulness' and 'validity' of our own constructions (as well as others) as constituting 'reality', these constructions themselves form the basis for any analysis of future reconstruction, future interpretation or future action. This means that our present and future reality is framed by own idiosyncratic construction which might be useful in drawing attention to interesting phenomena but might equally limit our attention or fail to illuminate our assumptions to other aspects. Furthermore; "all the techniques rely on the ability of participants to introspect, to reflect on their experiences and assume....that this can be captured and communicated via language.....Some experiences are completely beyond words: e.g. listening to music."(ibid). Such an approach is also very dependant upon the ability of the participants to relate effectively with one another and may make it difficult to assess unconscious motives. Who unearths them, who assesses them?

Bannister et al highlighted a number of other problems. The method encourages a belief in 'reification' the belief that some objective truth has been uncovered rather than a construction of a section of someone else's understanding. Such constructs also tend to oversimplify experience because there "are dimensions, not either/ors." This approach hinges on the idea that the world is comprised of processes (constructs) rather than things

(concepts). These methods can also be criticised as neglecting the socio-cultural context in two respects. Firstly "the format of Kelly's language and his use of language illustrate his firm grounding in the times and his personal biography." Secondly, whilst Kelly recognised that "he was aware of the impact of culture on people's construing....the emphasis is on *individuals* as agents of their own actions, shaping themselves by attaching personal meanings to what is going on rather than shaped via social construction; that is a personal rather than a social construction." This may mean that by relying on personal construct approaches "we may fail to consider how our particular position in our sociocultural context frames our reality and limits our choices." In defence it is argued that "the accounts we gain from personal construct approaches are explicitly subjective, which is indeed the aim and all that research can ever gain." (ibid)

Such a methodology seems inappropriate for this study for a number of reasons. Firstly, there were practical difficulties. My clinical practice was essentially composed of numerous short consultations. It might be possible to collect considerable quantities of data using repertory grids, but there would have been little opportunity to test the inferences developed during the research with the same group of patients who made them in the first place. The qualitative strength of the methodology rests principally with the interchange of data, with for example exchange grids, and the transient nature of patients in clinics would make such exchange impractical. In practice, this would mean that the data generated by such a methodology would essentially belong to, and be interpreted by, the researcher. Secondly, the essentially retrospective nature of the analysis did not allow a high degree of inquiry in the moment, during the clinic itself. This does not fit well with the intended research objective to ask more effective questions. Thirdly, there was no opportunity for myself, as the researcher, to test or be tested about the position I adopted both historically and culturally, and to gain a perspective on the 'value driven' nature of the data obtained. Finally, since the methodology depended upon a high degree of reflexivity, an inability to ask sensitive questions in the first place, how would I both develop and assess my own reflexivity during the research?

Discourse analysis

In 1992, I attended a qualitative health research conference and listened to a number of presentations that had utilised a methodology based around discourse analysis. This led me to consider whether a formal approach using discourse analysis might play a part in the research project. Discourse analysis treats the social world as text that can be systematically 'read' and takes the view that language is so structured as to produce sets of meanings, discourses, that operate independently of the intentions of speakers, or writers. "It is the discourses that 'form the objects of which they speak', and not authors who speak through the text as if the text were a kind of transparent screen upon which the writer's intentions are displayed." (Banister, Burman, et al.1994 p100) Most texts convey assumptions about the nature of the individual's psychology, which can be at least partly understood by careful analysis. Such discourse is created in a number of ways and may be analysed by examining;

1. The officially recognised idioms (i.e. ways of talking about needs, rights and interests)
2. The vocabularies available (e.g. feminist, therapeutic, religious etc)
3. The paradigms of articulation that are accepted as authoritative
4. The narrative conventions available for constructing the individual and collective stories that constitute people's identities.
5. The modes of subjectification: or the ways in which various discourses position the people to whom they are addressed as for example, 'normal' or 'deviant'.

(Vince 1996 p134-135)

Discourse can be seen as an expression of the relationship between language (in a very broad sense) and power." (ibid). For example, if I say "I am dizzy, therefore I have an illness," I am employing a medical discourse. If I say "I am dizzy, therefore I cannot work,", I am employing a psychodynamic discourse. If I say "that patient is dizzy and this is a more common complaint in women, " I am employing a sexist discourse. A phrase " that female patient is dizzy, thinks that they are seriously ill, but there is really nothing

wrong with them and they should be back at work," then all three discourses are at work. The task in discourse analysis is to separate out these discourses.

Discourse analysis seeks to uncover the network of relationships that people, institutions and different social worlds develop as they interact. An analysis of texts or speech identifies discrete relationships that are at work and which may have otherwise passed unnoticed. These might be rational rule following, parental, developmental or medical so that discourse analysis would also include an assessment of; "where and when these discourses developed, a description of how they have operated to naturalise the things they refer to, that is how they 'form the objects of which they speak' and how discourses have a role in reproducing institutions. Also how these discourses might subvert those institutions, which leads onto an exploration of who would benefit and who would be disadvantaged by such discourses and who would want to support or credit such ways of talking." (Banister, Burman, et al.1994 p103) In the medical world, development of 'evidence based medicine' can be seen as a bulwark against 'charlatanism' (alternative medicine) and as a defence of a 'correct' medical practice. Medical institutions such as the Royal College of Surgeons do not simply structure social life, they also constrain what can be said, who can say it and how people may act and conceive their own agency and subjectivity. In this respect discourse analysis is useful because it acknowledges the connection between language and power. "The concept of power is vital to discourse analysis via the theoretical connection between the production of discourses and the exercise of power."(Jupp & Norris 1993 p48) This whole notion has been considerably developed by Foucault who asserted that "Power produces knowledge, they imply one another: a site where power is exercised is also a place where knowledge is produced" (Foucault, M. 1975).

What are the limitations of discourse analysis? Discourse analysis assumes that there is no such thing as a fundamental and universal discourse which is shared by all. In this sense discourse analysis is at odds with a structuralist position which holds that language has an underlying structure and therefore is a common code. This does not mean that there is no possibility of a universal code, simply that discourse analysis "rejects the

notion that universality is inevitable." (Jupp & Norris 1993 p47) This alerts one to the possibility that texts are not as coherent as they first seem and are constructed out of cultural resources, e.g. scientists use empiricist (resting on evidence) and contingent (relying on intuition) arguments to account for their choice of theory to the scientific community.(Squire,C. 1990 p33-46) It can be argued therefore that knowledge and discourses must be analysed in terms of different points or stages in history, and also in terms of social relations prevailing at these points rather than in terms of individual constructions. Such an approach would be impossible by relying on the analysis of speech or text alone.

Discourse analysis has a superficial attraction by virtue of its semi logical common sense and the way in which the analysis presupposes what it pretends to discover. This can be regarded as a tendency to reification, an emphasis on self-referencing, as well as the assumption that the 'analyst knows best', an assumption incidentally that guides much positivist research. In the search for explanatory clear analysis, the method may overlook resistance and contradictions in the reader and the writer of any text.(Bannister & Burman et al 1994 p103) Validation of any discourse analysis is a problem and much of the analysis may be speculative especially if the work is done alone, which given the nature and time constraints of a clinic might well be the case. One possibility to overcome this would be to have taped the interview and examined at a later stage a transcript. My preoccupation, during the early stages of the research, with a methodology that explored inquiry *in the moment* meant that I put aside this approach. In the latter stages of the thesis, when the importance of the relationship between power and language became clearer, I returned to this idea and made videos of consultations and longer interviews (mentioned earlier). I do not claim to have approached the task of analysing the text in a systematic manner demanded by a rigorous discourse analysis methodology, however, I do claim it stimulated my interest in the power relationships that underpin language. These relationships are discussed in more detail later in the thesis when I attempt an analysis of clinical power relations. Finally it is almost self evident that; "there is more *variability* in human action and experience than can be expressed in language; as researchers we *construct* our own image of the world when we reconstruct 'discourses';

and we have some responsibility for how our analysis will *function.*" (Banister, Burman, et al. 1994 p106)

Action methodologies

This final group of methodologies form one pole of a range of methodologies characterised by two features in particular; they are both more prospective in intention and they emphasise the importance of action. The methodologies described so far have by and large been retrospective in nature; observation, surveys, discourse analysis all seek to throw light on processes in a retrospective fashion. Any understandings of a situation are framed by an attitude that is embedded within a methodology that is forever analysing retrospectively. At one level all understandings and analysis are retrospective but in the methodologies that are about to be described there is an emphasis on attempting to understand *in the moment* and such understandings in the moment provide the opportunity for *inquiry* in the moment and *intervention* in the moment. There is thus an emphasis on *exploration* rather than testing of hypotheses. Secondly, the methodologies described so far avoid considering in detail the place of action or what has been called intervention effects. Analysis has a more static flavour and the place of knowledge related to action or intervention or practice is by and large ignored. The following 'action' methodologies seek to place more centrally the role of action as a feature of everyday experience and in particular professional practice. For these reasons I perceived that an action methodology of one sort or another would be likely to play a central part in the research undertaken in this thesis.

Within these action methodologies the whole range of paradigmatic approaches can be found, from positivism to participative. For example, at one pole 'experiments, quasi experiments and single case research' can be seen to arise from the positivist tradition of experimentation, although in their qualitative application they might be positioned as post-positivist in terms of paradigm. The researcher and the researched are regarded as separate, and agendas are researcher controlled. At the other pole, the co-operative inquiry model of action research seeks to adopt a democratic approach to agenda setting

and examines the politics and power structures of researcher and researched in an attempt to regard all participants as co-inquirers. These action methodologies will be reviewed in turn, starting with the more positivist orientated and finishing with the more participative action methodologies.

Experiments, Quasi experiments and single case research

This group of methodologies is characterised by a basic design of baseline assessment followed by intervention which is then repeated over a period of time. This *continuous assessment* of some aspect of human behaviour over a period of time requires, on the part of the researcher, the administration of measures on multiple occasions within separate phases of a study. "They involve what is termed *intervention effects* which are replicated in the subject over time. Continuous assessment measures are used as a basis for drawing inferences about the effectiveness of intervention procedures." (Cohen & Manion 1989 p210) The methodology may be undertaken with groups or the individual. "The single case research design is uniquely able to provide an experimental technique for evaluating interventions for the individual subject. Moreover such interventions can be directed towards the particular group and replicated over time or across behaviours, situations or persons." (ibid)

As a doctor, such a design seems very familiar. It seems to me to describe the implicit methodology one 'instinctively' employs as a doctor. A patient will present a problem to the doctor in the clinic after which the doctor makes an assessment and then recommends an intervention such as medical treatment or surgery. After a suitable period of time, the patient will be reassessed and further interventions will be considered and tried. The method is validated by discharge from the clinic, indeed a current indicator of effectiveness of a doctor or a medical unit is the 'finished consultant episode'. Use of such a methodology would offer no more than a more rigorous application of what is already happening. It seemed to me that if my espoused approach was to try and develop

a research protocol that sought to offer an alternative ontological viewpoint, such an approach, firmly based in the post-positivist paradigm, would fail to do so.

Ethnography

Ethnography originates from the cultural and social anthropologists of the late nineteenth century and early twentieth century. Their characteristic approach was to collect data firsthand. Ethnographers concluded that "understandings of the character of non-Western societies were shaped by Western interest and the various motives that underlie those interests." (Atkinson & Hammersley 1994 p249-250) Furthermore these understandings themselves also reflected the influence of historicism for central to this approach is the assumption that people of the past were different in culture from the people of today. This is not just a matter of recognition of differences but also the judgement that these differences cannot be properly understood by seeing them in terms of the "deviation from the norms of an observer's different historical perspective nor as signs of cultural backwardness." (ibid) It was not long before this cultural and historical perspective was applied to contemporaneous societies and to the study of one's own social surroundings as well. From the ethnographers perspective all knowledge has to be understood within its cultural and historical framework. (ibid)

In practice then, what are the components of an ethnographic approach? At its simplest; "It is a basic form of social research involving making observations, gaining data from informants, constructing hypotheses and acting upon them." (Bannister & Burman, et al. 1994 p34) but in practice a multimethod approach is used that is characterized by:

1. Gathering data from a range of sources, e.g. interviews, conversations, observations, documents.
2. A strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them.

3. In the early stages, using an unstructured approach to analysing data. This is data that has not been coded at the point of data collection in terms of a closed set of analytic categories. This is so that key issues can emerge gradually through analysis.
4. Analysis of data that involves explicit interpretation of meanings and functions of human action, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most.
5. Comprising an in-depth study of one or two situations
(Banister, Burman, et al. 1994 p34-48; Atkinson & Hammersley 1994 p248-261)

The first issue to consider is the degree of participation on the part of the researcher and in this respect there is considerable variation. At one pole, ethnography refers to a paradigm to which one makes a total commitment; "it has to be involved, committed, relevant, intuitive, but above all it has to be alive." (Reason & Rowan 1981 p35) It is believed that this involvement and commitment ensures "that theories are developed and tested during the process of research itself" (Glaser & Strauss 1967) At the other pole participation may be much capricious so that ethnography represents "a method that one uses as and when appropriate." (Atkinson & Hammersley 1994 p248-249) Of course there are intermediate positions within these extremes.

An attempt has been made to clarify this degree of participation and a fourfold topological description has been developed ranging from "complete observer, observer as participant, participant as observer to complete participant." (ibid) Even this approach fails to appreciate the multitude of variations of participant involvement possible such as "whether the researcher is known to be a researcher by all those being studied, or only by some or by none; how much, and what, is known about the research and by whom; what sorts of activities are and are not engaged in by the researcher in the field and how this locates him or her in relation to the various conceptions of category and group membership used by the participants; what the orientation of the researcher is; how completely he or she consciously adopts the orientation of insider of outsider." (ibid)

Some would argue that it is ontologically impossible to act as a researcher without being able to avoid having an effect on the social phenomenon being studied. This point of view suggests that it is better to understand, rather than overlook, the effects of the researcher. Reason and Rowan (Reason & Rowan 1981)have also argued that attempts to make it 'scientific' by setting up experimental method, quasi-experimental method tests of significance, dependent and independent variables destroys the quality of research and leaves only 'dead knowledge'. Understandings are also strengthened if "the findings are based on several different sources of information in a corroborative mode." (Banister, Burman, et al. 1994 p37)

Given this assertion then, one might argue that the ethnographer aspires to participate actively in the research environment but does not structure it; the approach is discovery based, the aim being to depict the activities and perspectives of actors. (Banister, Burman, et al. 1994 p34) In practical terms one approach to this would be to more clearly position oneself as a 'researcher' and adopt a role that regards participant observation as a mode of being in the world characteristic of researchers. Within this framework the researcher should be alive to the degree of participation in a reflexive manner and in the process be aware of adopting a research stance that may be 'scientific' (essentially observer/researcher) or engaged advocacy (essentially researcher/participator) or critical stance (intermediate position). (Atkinson & Hammersley 1994 p249) These basic positions place the researcher within a post-positivist, constructivist or critical theory paradigm respectively. Given the range of paradigms possible with ethnography, it would seem particularly important to understand ones paradigmatic standpoint so that the ontological, epistemological and methodological positions were coherent.

This approach may be acceptable when engaged in what has been called the 'enlightenment model' of ethnographic research but becomes more complex if as researcher one finds oneself engaged in the process of change. In the 'enlightenment' model, knowledge obtained during the course of the research is regarded as useful for its own sake and contributes towards disciplinary knowledge rather than solving practical problems. However, this model has been criticised as lacking sufficient impact and has

given rise to more collaborative, participative and involved forms of ethnographic research. This makes the question of participation much more problematic, for in this kind of research the researcher may be obliged to consider when to intervene or represent others when ethical and political responsibilities arise from knowledge obtained during the course of the research. (Atkinson & Hammersley 1994 p253) This is precisely the position I might find myself having to consider when engaged in research of a process in which I am not only a participator but also a significant protagonist. It suggests that stand alone ethnography might be to permit ethical and political issues to emerge, be discussed and if necessary acted upon.

The historical and cultural origins of ethnography suggest all understandings have to be understood within a cultural and historical framework, which would seem to encourage an ontology that is multi-perspectival. This evolution of perspectives resulted in a profusion of types of ethnographic research. Ethnographers "meet and coalesce to form various 'schools' or subtypes of ethnography; they engage with different theoretical movements and fashions (structural functionalism, symbolic interactionism, cultural and cognitive anthropology, feminism, Marxism, ethnomethodology, critical theory, cultural studies, post-modernism and so on). There is never an orthodoxy....such research is marked by diversity rather than consensus" (Atkinson & Hammersley 1994 p257)

For example "feminist ethnographers have argued that the findings of much research simply reflects the masculine assumptions of workers.....the whole perspective is limited by their male point of view." (ibid) This diversity, as I see it, is both a strength and a weakness. The attraction of ethnography is that it constantly reminds the researcher about the connection between values, power, history and 'facts'. It emphasises the context of any epistemological position. The problems arise because this approach eventually makes one question the context of the methodology itself. Is the methodology utilised to generate knowledge itself a value mediated, culturally influenced historically imprisoned methodology? If so then one should certainly go on to question the status of knowledge generated by such a methodology. For example does my position as a white middle class professional male in the late twentieth century in a profession such as surgery, that may

be action and decision orientated, influence me to chose a methodology with a high degree of intervention and participation to study social phenomenon? The answer is likely to be 'yes', so that "the ways in which we theorize a problem will affect the ways in which we examine it, and the ways in which we explore a problem will affect the explanation we give. " (Banister, Burman, et al. 1994 p13) Such an approach has been criticised on the grounds that the diversity of the ethnographic approach encourages naïve inquiry. So how does one avoid naïve inquiry?

In order to avoid the charge of naïve inquiry, it has been argued that "knowledge should include empirically disconfirmable propositions that can be organised into theory and falsified by practitioners in real-life contexts." (Argyris, Putnam, et al. 1985 p232) This means in practice that participants should be given the opportunity to accept or reject propositions made about them. An action scientist might argue that ethnography, as a methodology, does not contain a sufficiently consistent and validated theory to overcome this problem. The ethnographer might reply that the principle of reflexivity, that is how the researchers position themselves within the context, process and production of the research, is of central importance and that if this is done sufficiently well then naïve inquiry is avoided. (Banister, Burman, et al. 1994 p37) Naïve inquiry is also made less likely by aiming to make a virtue out of such subjectivity by "an exploration of the ways in which the subjectivity of the researcher has structured the way it is defined in the first place." In this manner "subjectivity becomes a resource, not a problem." (ibid)

This is particularly relevant when one considers for a moment the nature of my practice and how I was researching it prior to the onset of this more formal research project. At one level my clinical practice and understandings that developed within this practice represented a form of ethnographic research. Some might argue it was weak 'research' because it lacked sufficient reflexivity. As a clinical 'ethnographer' I would attempt to impose meanings on the clinical settings and specifically make inferences about patients, guided by whatever theoretical perspective has helped me to frame this data, largely positivist or more likely post-positivist. This meant making little or no attempt to publicly test my inferences (or the theories on which they are based) with the patients and

ultimately ended up imposing meanings on situations that may not have been accurate. This made real learning less likely. "All ethnographers must impose meanings on their settings, specifically such chains of reasoning went untested." (Argyris, Putnam, et al. 1985 p158) This approach may have mirrored the way I had been taught.

When considering ethnography as a methodology, I was left thinking that it would be insufficient as a stand-alone methodology for a number of reasons. It does not provide a suitable framework to handle ethical and political issues that might arise during the course of 'enlightenment'. It may be difficult to question the degree of participation I take as a researcher and participator. There is no mechanism to develop and validate the degree of reflexivity I may or may not display. It contains no mechanism within the methodology to analyse the meaning of 'knowledge in action' that would seem to be important in any study of professional practice. Finally, and most important of all, I intuitively appreciate, the method is insufficiently different from what I was already engaged in trying to do to provide that 'jolt' that leads to real change in perspectives.

One is left to consider the possibility of a hybrid methodology which includes 'participant observation', in particular, which many researchers see as synonymous with ethnography, as forming the base method, while 'interviewing and action research' form later stages. Such a model would be consistent with a constructivist ontology and epistemology. (Banister, Burman, et al. 1994 p35)

I have chosen this point to consider the methodology utilised by my supervisors in the supervisory process of my own research. In the formal model of supervision, we would meet to discuss the project (data collection), infer (construct hypotheses), suggest a plan of action (act on it) and arrange to meet again (repeat the process). The sample for the study (me) is a single, in depth study conducted over a long period of time. Supervision like this (but not participation in the post graduate research group to be discussed later) would seem to be a simplified if not especially rigorous form of ethnographic research. So within this methodology, what degree of participation do I expect or experience from the supervision process? Where, within the fourfold typology of participation, do they

position themselves and where would I position them; complete observer, observer as participant, participant as observer or complete participant? This question may be particularly relevant as one (Peter Reason) has espoused in print the belief that ethnographic research needs to be genuinely participative, involved and committed. If so then to what degree am I subject to the political and ethical stance that my supervisors adopt? Similarly to what extent are they subject to the political and ethical stance that I adopt? These and other questions suggest that it is necessary for the supervision process itself to have a methodology that allows such issues as these and others to have a voice. It suggests that my own methodology must at least consider if not develop a strategy to evaluate this position.

Action research

Within the formal term 'action research' are several action methodologies which each claim to possess a distinctive approach and these have from time to time coined particular terms for themselves. For example, Argyris, concerned at the way that action research had separated theory building from testing, preferred the term 'action science' to distinguish this approach from mainstream action research. (Argyris, Putnam, et al. 1985 pix-xv) This short review will aim to examine the methodological approaches that characterise action research but will also review three approaches in particular. These are the 'action science' methodologies of both Argyris and Schon because of their emphasis on professional practice and the 'action inquiry' methodology of Torbert because of its espoused usefulness in situations involving groups and it's attention to justice.

Action research developed from the work of Kurt Lewin. His basis for developing an approach that challenged contemporary social science thinking in the 1940's was concern about the power relationship between researcher and researched. At the heart of this was the perceived notion of the day that researchers were identical, infallible, unbiased measuring instruments. These assumptions gave any research findings a kind of scientific rigor and, as a result, qualitative research "tended to devalue the accounts from

researched in favour of those from 'professionals'." (Banister, Burman, et al. 1994 p110) In paradigm terms, such an approach would be regarded as essentially post-positivist although the proponents of such an approach might have seen themselves as positivist or neo-positivist. Lewin recognised the fallibility of this approach and advocated that "a pluralist approach was a consequence of the fact that researchers needed to interact".(ibid) In such an interaction bias, fallibility and difference were all recognised features of any researcher just as they are features of 'the researched'. In this sense, this can be seen as the early beginnings of a change in approach which has culminated in the current belief, which "accords 'equality of status' to those who are researched." (ibid) With this in mind, he proposed the idea that social phenomena could be studied by "changing them and observing the effects, which in essence is the argument that in order to gain insight into a process one must create a change and then observe the variable effects and new dynamics." (ibid) This position advances the view that bias and difference cannot be eliminated and so are best appreciated by introducing change within a situation and adopting a critical interpretative view. In this respect action research makes an important assumption; it assumes that action and interpretation are distinguishable. This may not be wholly tenable for whilst analysis and action may be conceptually distinguishable, they are "inextricably intertwined in practice". (ibid) Problems associated with this apparent separation continually challenge the methodological integrity of action research.

How, then is 'action research' defined? In broadly methodological terms it has been defined as "a way of trying out changes and seeing what happens". This means that it is research that it is an "essentially on-the-spot procedure designed to deal with a concrete problem in an immediate situation" (Cohen & Manion 1980 p47). In this respect, it emphasises the situational aspect of action research; it is concerned with diagnosis of a problem in a specific context. In determining context, important questions outlining the degree of collaboration and participation of all members need to be addressed. Some members may wish to be more collaborative or more participative and this degree of interest is likely to be related to the question of purpose, purpose in participation, for collaboration or in doing research.

Carr and Kemmis have identified three main reasons for groups or practitioners to engage in action research. These include aiming to improve "the rationality and justice of (a) their own social or educational practices, (b) their understanding of these practices, and (c) the situations in which these practices are carried out." (Carr & Kemmis 1983 p151-202) Feminist researchers have developed this somewhat and identified five varieties of engagement in action research that can also shed light on underlying purpose. They have called these 'action research', 'participatory/collaborative research', 'prevalence and needs assessment', 'evaluation' research and 'demystification'. (Reinharz 1992.) In action research, action and evaluation proceed separately but simultaneously. Participatory/ collaborative research specifically emphasises that the people studied make the decisions. The particular ethical stance here is that they are co-researchers rather than research subjects. Prevalence and needs assessment varieties of action research seek to determine the absolute or relative number of people with a particular experience or need. Such research doesn't rely on surveys but on people meeting to understand their own experience and develop common themes, which lead in time to the size of the problem becoming evident. The act of gathering data and the manner in which it is gathered form the first part of a process leading to significant change. Evaluation research aims to assess the effectiveness of different types of action in meeting needs or solving problems. This leads to data based advice on what to do in certain situations e.g. "how to stop a rape and such information may be disseminated to other organisations." (ibid) Finally, demystification action research advocates that the very act of obtaining knowledge creates the potential for change. It is the converse of the belief that if the views of certain groups are unknown then they have less opportunity to influence certain situations. (Reinharz 1992)

The above considerations of context, collaboration, participation and purpose are not unique to action research and form components that need addressing with most forms of qualitative research. The key feature, which some might argue to be both the unique strength (and weakness) of action research, lies in the self-evaluative nature of the methodology. It can claim to "give 'practitioners' the kind of knowledge they can apply to

their own behaviour in the midst of on-going events, in such a way that it helps them acquire more effectively with others about their common purpose." (Banister, Burman, et al. 1994 p110) Self-evaluation is a necessary component of action research because only the researcher (in the broad sense of participant researcher) is able to evaluate his or her behaviour, which in turn leads (hopefully) to improved behaviour as a practitioner. This self-evaluative model can lead to self-referencing validation if no attempt is made to develop a sense of *critical* self-evaluation, and much of the methodology devotes itself to addressing this issue.

Action research is carried out as a stepwise process that monitors change over varying periods of time and by a variety of techniques. These include the use of "diaries, interviews, case studies, discussion, etc.," to generate feedback that leads to critical self-evaluation which may be "translated into modifications, adjustments, directional changes, redefinitions as necessary." (Cohen & Manion 1980 p47) The process is one of systematic, cyclical change. The research 'question' arises out of the problem of practitioners. The immediate aim of the research, as opposed to more long term secondary aims outlined above, is to understand these problems, and the researcher, who may or may not be the actual practitioner, "formulates speculative and tentative general principles about the problems that have been identified." From these speculations hypotheses are generated about the outcome and what action is likely to lead to desired improvements. The action can then be tried out and data on the expected and unexpected outcomes collected, which is used to revise the earlier hypothesis and generate new hypotheses.(Banister, Burman, et al. 1994 p110)

What constitute what Carr and Kemmis (Carr & Kemmis 1983 p159-160) have called the 'objects' of action research? What is to be examined, what is to constitute data, what form the basis for hypothesis building? The 'objects' of medical action research are medical practices. These are not mere techniques nor expressions of practitioners' intentions and perspectives in relation to particular historical circumstances nor behaviour as a technical means to a desired end "but a specific social practice to be defined in a particular situation." By 'a specific social practice', is meant "a strategic act; an act

consciously and deliberately undertaken on the basis of rational reflection by the practitioner, rather than on the basis of custom, habit, unreflective perception, or heresay. A human action, as opposed to mere behaviour, is a 'probe' into an unknown future." (ibid) Strategic action is "constructed" and essentially risky. It takes place "in the space between the foreseen and the unforeseeable, the intentional and the actual, the 'is' and the 'ought.' It reconstructs past action on the basis of observation and future action in the light of reflection." (ibid)

What is the role of theory in determining a) explanation and b) justification of such 'strategic acts.' Behaviour "might be retrospectively explained by reference to theoretical or empirical propositions, but it cannot be justified by appeal to these propositions." (ibid) In other words, theory can inform and explain action and even challenge action but cannot determine whether an action is justified or not. Practical action "must be justified by reference to the practical judgement of the practitioner as well as the circumstances and determinants which constrain action." (ibid) This suggests that practice has embedded within it, a kind of knowledge, a personal knowledge of justification, which is inaccessible to theoretical critique. "It implies that the actor alone has to be the final arbiter of the truth of an interpretation, not rules or principles of theories." (ibid) It does not imply that the "actor is impervious to the rational reflection of others" but that in the final analysis acceptance or not is dependent upon whether the arguments are sufficiently "compelling in the light of his or her authentic knowledge." (ibid)

This argument is closely allied to the criteria discussed a little later that determine validity. These are largely based on plausibility so that it is hardly inconsistent if the practitioner expects any arguments that inform action to be equally plausible. This suggests that in order to convince others it is important to pay attention to interpretation that goes beyond the level of personal experience to dismantle a charge of self-referencing interpretation. A key process here is to collect data that will inform the researcher in a way that goes beyond personal experience, to challenge personal assumptions, but in a way that does not significantly undermine practice. (Banister,

Burman, et al. 1994 p114) In other words that an act of interpretation does not in itself constitute 'action'. Of course, this may not necessarily be so, so what is to be done?

One important way to partly overcome this difficulty, and which certainly makes the conceptual separation of practice and interpretation less of a problem in theory, is by the use of tape or video recordings. In a way, such recordings hold time constant and allow a shift in place so that 'events' can be examined afterwards at a moment independent of action. Such a procedure can achieve a certain separation of interpretation and action. It allows some slowing down of interpretation to be made but also allows an opportunity for triangulation because others may offer alternative interpretation that challenge the researcher's ontology. (ibid) What is the methodological justification in doing this? Does it really constitute a sound methodological approach given the impoverished perspective even a good video recording might offer one? For even if one is sympathetic to the approach, there is still the possible reaction "You should have been there."

However, using recordings may be justified in two ways. Firstly it might overcome the problem of "relating retrospective understanding...to prospective action and plans for action." It bridges the "gap between past and future in systematic learning." (Carr & Kemmis 1983 p163) As such it is seen as essentially a transitory phase to enable a critical self-evaluative mode to be developed. Secondly, it forces the practitioner to focus on and question how an action is verified. "The pragmatist theory of verification requires that we act on our beliefs to see whether they produce consequences that we should expect of our beliefs are warranted." (Susman 1983 p100) This process is undertaken through hindsight, during which our actions are affirmed or transformed by an analysis that suggests different actions if we are faced with similar circumstances. Such a retrospective challenge to our interpretations that may be offered by others is thought to encourage the development of a critical self-evaluative approach. "It is the capability of the planner rather than the validity of the plan that is being improved by the process". (ibid)

This in turn suggests a twofold approach to assessment. On the one hand, professional practice continues to hopefully improve by attention to what is happening at the

professional level. In my case I am working to become 'better' at being a doctor by understanding developments in medicine, by communicating with patients more satisfactorily, by becoming more aware of their concerns and desires, more aware of my own assumptions and much more. This relies on a model that is self-evaluating but also self-referencing. At another level, action research suggests it is possible to develop good research practice by paying attention to the level of evaluative critique that determines what is seen to be justified or not. Can I be sure that this is what is going on? Is my interpretation of what is happening in the patient's mind fully justified, even if they agree with my interpretation? What is my level of assumption here? The extent to which this second level can be developed would seem to be dependent upon the opportunities for alternative interpretation to enter the equation. If 'enough' alternative explanation is seen to enter the equation through input from others then such a model may still be self-evaluating but may also periodically break out of a loop of self-referencing justification. Arguments might begin to be seen to be plausible.

This leads one to ask the question; Can action research be undertaken as a solitary exercise? The above discussion would suggest that it may not be possible. For as Habermas has written; "the self-reflection lone subject...requires a quite paradoxical achievement: one part of the self must be split off from the other part in such a manner that the subject can be in a position to render aid to itself...in the act of self-reflection that subject can deceive itself." (Carr & Kemmis 1983 p171) It would appear that "the quintessence of both critical social science and action research is the group process of deliberation." What is the position of the sole practitioner anxious to develop his or her practice? Such arguments would indicate that some component of the methodology must have access to the interpretation of others.

How does all this relate to the actual procedures of action research? Susman and Evered (Susman & Evered 1978) identified five stages of diagnosing, action planning, action taking, evaluating, and specifying learning. They regarded the diagnosing stage as a problematic stage that "provided the energy needed to work on the problem." Action planning and action taking was "a search for the best solution to what appears to be a set

of conflicting requirements between a social and a technical system." (ibid) This approach takes the stance that any difference that exists between two systems is more apparent than real because they are based on different epistemological assumptions. This is a useful approach to adopt because clinical medicine offers an interpretation that is one of espoused positivism. In adopting a constructivist epistemology as an alternative explanation it may be possible to produce knowledge which, whilst not easily translatable or comprehensible to the other, is likely to be informative. It may produce understandings that are not otherwise attainable.

The process of evaluating process asks four key questions;
1. Did the actions bring about the conditions that the sociotechnical model led us to hypothesize will produce the outcomes desired?
2. Were the desired outcomes produced?
3. If so, how confident are we that it was the hypothesized conditions that produced them?
4. If not, what aspects of the socio-technical model should be re-examined?

The final process of specifying learning draws attention to what has been learnt not just in terms of what has been transformed by the inquiry, but what methodological capabilities have been developed by actually undertaking the inquiry. (Susman 1983 p110)

In emphasising a more co-operative approach to action inquiry Cohen and Manion have developed a number of discrete stages to be considered in action research undertaken within groups;
1. Identification, evaluation and formulation of the problem.
2. Preliminary discussion and negotiation among interested parties. Objectives, purposes and assumptions need to be made clear to participants.
3. Review of the research literature for evaluation of comparable studies
4. Modification or redefinition of the original 'problem'. This may emerge as a testable hypothesis.

5. Selection of research procedures; sampling, administration, choice of materials, methods of teaching and learning, allocation of tasks.
6. Choice of evaluation procedures to be utilised.
7. Implementation of the project. This stage includes conditions and methods of data collection; the monitoring of tasks an the transmission of feedback; the classification and the analysis of data.
8. Interpretation of data; inferences to be drawn; overall evaluation of the project.

They also identify various means of intervening to generate change. These include interventions that;

1. act as a spur to action
2. address itself to personal functioning, human relations and morale
3. focuss on job analysis
4. are concerned with organisational change
5. are concerned with planning and policy making
6. are concerned with innovation and change
7. concentrate on problem solving in virtually any context
8. provide the opportunity to develop theoretical knowledge.

(Cohen & Manion 1989 p218-219)

Theory building is developed around the four key moments of action research, which have been described thus:

	Reconstructive	Constructive
Discourse (among participants)	4 Reflect *Retrospective* on observation	1 Plan *Prospective* to action
Practice (in the social context)	3 Observe *Prospective* for reflection	2 Act *Retrospective* guidance from planning

The theory axis is the discourse axis during which outcomes are assessed during reflection and new hypotheses are generated during planning to gradually develop theory. (Carr & Kemmis 1983 p163-164) It seems agreed that a series of cycles are needed to develop a sufficiently rich interpretation. Some have expressed doubt whether "a single loop can be considered as action research at all." For "if what is learned in one cycle is not applied judiciously in further cycles of modifying plans, implementing them, monitoring the ammended action, and reflecting again, then the action research process disintegrates into mere problem solving or exercises in rationalisation of action. We call single loop activities '*arrested action research*'." (ibid) Even so, such arrested action research may still be useful in that it may prompt questions as to why it failed to develop. What was it about the organisation that discouraged such an approach and how does this inform the researcher? Is there something about the institution that served to maintain the status quo?

Finally, how does action research address the status of propositional knowledge? Some might argue that this is not even necessary. After all the aim of action research is to inform the practitioner and simply partaking in an action inquiry will in some way do this. Others, however, might take the opposite view and consider that "knowledge should include empirically disconfirmable propositions that can be organised into theory and falsified by practitioners in real-life context." (Argyris, Putnam, et al. 1985 p232) In

practice this means that participants should be given the opportunity to accept or reject propositions made about them.

Carr and Kemmis have drawn on the work of Habermas and suggested three separate criteria for the evaluation of action research; through discourse, enlightenment and prudent decision making. Firstly, "the truth of statements is evaluated through the discourse which raises, recognises, and redeems 'validity claims'." Any assertion is dependent upon the following for its claim to validity (after Habermas)

1. Is what is stated comprehensible?
2. Is what is stated true?
3. Is what is stated right and appropriate?
4. Is what is stated sincerely and truthfully stated?

Secondly, at the level of enlightenment, "the criterion is authentic insights, grounded in participant's own circumstances and experiences." Lastly at the level of organisation of action, the criterion is prudent decision making."
(Carr & Kemmis 1983 p178-179)

With this general picture in mind, I propose to examine in more detail the 'action science' methodologies of Argyris et al and Schon and 'action inquiry' as described by Torbert.

Action Science

Argyris et al introduced the term 'action science' because of concerns about the separation of action research from theory building and testing. They observed that in order to "conduct their empirical work by following current ideas about standard scientific research and to attain a certain level of rigor, the methodology may become so disconnected from the reality it is designed to understand that it is no longer useful." (Argyris, Putnam, et al. 1985 px) They saw the root cause of this as the separation between the work of the basic scientist who generated "fundamental generalizable

knowledge" that is then put into practice by the applied scientist. This process, this relationship "reinforces a pernicious separation of theory and practice." (ibid) This is exemplified in the emphasis placed upon knowledge gained from the use of questionnaires. Such knowledge, they felt, "cannot rest solely on the analysis of social statistics. It is necessary to get at the meanings embedded in action, at the logic of action." (Argyris, Putnam, et al. 1985 p26)

Action science is a theory about human action, which can be tested in a number of ways; through group activity, one to one consultation, in learning environments etc. This interaction results in data that is then used to test whether the theory is generalisable to other groups in other situations. A key feature then was to develop "empirically disconfirmable propositions that are organised into theory. Knowledge that human beings can implement in an action context" that lead to the development of "alternatives to the status quo that both illuminate what exists and inform fundamental change, in light of values freely chosen by social actors." (Argyris, Putnam, et al. 1985 p36-79) Attention is shifted from the 'outcomes' of an action science inquiry towards an emphasis on 'process' in action inquiry. The action scientist is seen as an interventionist, who promotes learning "by creating conditions for valid inquiry in the context of practical deliberation by members of client systems." The practice of action science involves "teaching others the skills needed to practice action science." (ibid)

A particular feature of this skill is to understand the place of defensive routines, which were seen as serving to maintain the status quo which researchers may encounter. They asserted that "as the primary object of science is to describe reality, it cannot describe the defensive routines that protect the status quo against change." Even when social scientists recognised defensive routines, "to point to the positive aspects of defensive routines as reasons for not studying how to change their negative aspects may itself be a defensive routine." The culmination of this may be when social scientists are denied access by subjects to research material, and are excluded from research projects when groups, preferring to leave issues undiscussed, unite against a researcher. (Argyris, Putnam, et al. 1985 pxii-xiii) The powerful message of Argyris work is that "these defensive routines

are alterable." (Ryan 1985) This approach places action science firmly within the paradigm of the critical theory, propective transformation tradition.(Watkins 1988)

The task of developing an action science to make practical knowledge "explicit and testable" is aided by focussing upon the three main features that constitute an epistemology of practice. Argyris highlighted *problem setting*, *tacit knowing* and *reflecting and acting*. Problem setting means particular attention to framing the context of the problem. Questions are framed in such a way that they not only ask "Why is it like this?" but also at the same time ask "How is it possible to change what is discovered?" Such framing then, not only defines the problem and "defines what is to count as a solution" but it may also "elucidate the actor's purpose." It is this notion of "purposiveness" that is central to the concept of action. "Purpose in context leads to meaning".(Argyris, Putnam, et al 1985 p45) An assumption underpins this position. It presupposes that intention and purpose is followed by a strategy that is necessarily linked to that purpose to achieve that end. That may be fair but it also assumes that this linkage is reducible to an analysis that explains this linkage in a coherent manner, one that holds plausibility. Is this always the case? For example, the actions of a madman appear to be 'mad' to the rest of us because behaviour (strategy) may not be coherently linked to purpose. It is an assumption we make that there is a sharp distinction here between the sane world and the mad world and that those in the sane world do not, from time to time, adopt a strategy that is not coherently linked to purpose. I am not sure that this is necessarily the case because it would depend upon a rather naïve definition of madness.

The second epistemological feature is tacit knowing. "It is characteristic of action that most of the knowledge informing it remains tacit." (Argyris, Putnam, et al. 1985 p50) Argyris likened this to the ability to "recognise one face among thousands despite the fact that we cannot tell how we know." It seems to me this simile is highlighting a distinction between recall and recognition for tacit knowing is 'knowing that we know' rather than being able to 'recall what we know.' It seems to me that it has much more to do with recognising that out of the many solutions or courses of action possible in a given

situation, we 'know' that the one selected is appropriate; it is about recognising certain patterns of action.

Finally, reflecting and acting "is a way of making explicit some of the tacit knowledge embedded in action so that the agent can figure out what to do differently." In this respect action may be a probe, a move or a hypothesis. The cycle is then repeated with a process of reframing. (Argyris, Putnam, et al. 1985 p5) In empirical terms this process is manifested largely through talk. The significance of this in clinical life is encapsulated by one of the amazingly simple insights about medical treatment; it is conducted in language. Talk is action and like all action, talk is meaningful. Failure to understand the interpretive nature of talk leads to problems of understanding and Argyris suggests a useful conceptual device, which he terms "the ladder of inference." This is a representation of the steps that we make when trying to develop meaning in everyday life.

1. Observable data e.g. sentence uttered by someone
2. Cultural meaning of that utterance (meaning that everyone in that cultural community understands)
3. Meaning imposed by the hearer (e.g. that utterance was 'blunt' or 'insensitive')

Argyris emphasised the importance of obtaining agreement at each level of the rung. Firstly, agree on what constitutes data, then obtain general agreement on cultural inference before finally trying to agree on meaning by the hearer. (Argyris, Putnam, et al. 1985 p58) An appreciation of the interpretive nature of talk expressed in this way, meant that I began to pay more attention to the way meaning was conveyed and the power issues embedded within it.

Patients may well present a history at either the level of observable data or at a level of cultural meaning. For example, one patient may describe their nasal symptoms more at the 'data' level in terms of being 'blocked' or 'runny' with a 'painful' face. Another patient may describe the same symptoms at a level of cultural meaning in terms of

'sinusitis' or 'allergy'; they have in the process made an assumption about the cause of such symptoms. Three issues arise here. Firstly, the process of presenting data on the second rung, the rung of cultural inference, means that assumptions are made by both parties about what is meant by this inference; we can both easily assume that we agree on what we mean by 'sinusitis' or 'allergy'. This agreement may not be valid if it is tested and this was reflected in a change in practice that sought to go back to data to seek agreement. What exactly do you mean by sinusitis? Could you use everyday unambiguous terms so that I really understand what you mean by being "dizzy"? Secondly, the conversion of data to the level of 'cultural inference' is the first part of the process that converts everyday language into 'biomedical' language, a form of knowledge that has medical control and power embedded within it. It may become much more difficult for non-positivist data to re-enter the positivist inference. For example, if the discussion between the patient and the doctor is utilising terms such as 'sinusistis' or 'allergy' this level of inference has already set up barriers that make it difficult for information such as 'acupuncture points' to be accepted. Finally, I began to appreciate that the biomedical inference I sought to impose on data was a theory and value dependant process supported by a belief in 'usefulness' determined by *my* criteria. This opened the way for me to take seriously other 'medical' interpretations made by the patient but utilising other theories and values on the same set of data, that data being the patient's symptoms of disease.

However, making interpretations is not thought to be straightforward. In trying to understand action or practice, action scientists draw a distinction not between theory and action but between two different theories; "those that people espouse and those that they use. Both theories may be consistent or inconsistent and furthermore the agent may not even be aware of any inconsistency." (Argyris, Putnam, et al. 1985 p82-83) They name these different theories, espoused theory and theory-in-use. Espoused theories are those theories "that an individual claims to follow, but theories in use are those that can be inferred." Theories in use are regarded as "tacit cognitive maps by which human beings design action." (ibid) The process of action science is to uncover such theories-in-use by learning to reflect-in-action, "making explicit the theories-in-use that inform it, and

learning to design and produce new theories-in-use for reflection and action." (ibid) How is this done?

All action has consequences and these consequences can be intended or unintended, productive or counterproductive. Particular interest is focussed on those consequences that are unintended or counterproductive. This is usually perceived as error, and the "first response to error is to search for "another action strategy that will satisfy the same governing variable e.g. suppression of unintended conflict. If agents wants to suppress conflict (governing variable) and to this end avoid saying anything that might be controversial (action strategy), but others raise threatening issues (mismatch), the agent may try the strategy of talking volubly about issues on which everyone agrees." An alternative approach here is to emphasise open inquiry rather than engage in suppressing it. They call this approach double loop learning for in this situation error is regarded as the raw data for learning. By focussing on double loop learning it becomes possible to examine the theories in use that inhibit it. (Argyris, Putnam, et al. 1985 p86) What is the relevance of this to clinical practice?

This concept of double loop learning began to influence the way I behaved as a doctor in certain situations, by turning a defensive or conflict situation into one that generated inquiry. If I sensed that the patient had begun to lose confidence in my abilities as a doctor I have two approaches; single loop learning or double loop learning. A single loop learning response would be to work hard to try and cover up conflict, probably talk more, suppress any conflict, all parts of a process aimed at denying to myself that a loss of confidence exists. My espoused theory is to 'gain confidence', my theory in use is to 'cover up' loss of confidence. I saw that a 'double loop' learning response would be to ask a question such as; I have a feeling that you have lost confidence in me. If this is the case would you like to suggest why this may be so? This served a number of purposes. Firstly, it checked out the third level of inference, the meaning imposed by the hearer. For if this inference is not correct, that confidence has not been lost, then the espoused theory (acting to gain confidence) needs to be addressed. If indeed confidence has been lost,

then the process reverts to an experimental intervention designed to throw light on why confidence has been lost, which may, in the process, elicit other theories in use.

Argyris developed five rules that assisted the process of eliciting theories in use. These are summarised below.

Rule 1. "Interrupt interactions on-line, direct attention to internal processes, and generate the impetus to explore them."
Rule 2. "Elicit the attributions and evaluations being made about self, other, or situational factors (such as task, time, and so forth)...we probe for these attributions."
Rule 3. "Regard causal explanations as hypotheses to be tested. As unreliable as self-explanations can be, we cannot a priori assume that they are inaccurate. They should be regarded as worthy of test like any other hypothesis... search for data that might falsify the proposition."
Rule 4. "Slow down and focus on the inferential steps individuals take in going from the data to their conclusions, since the very skilfulness of their inferential processes can cut individuals off from them...can help individuals spell out tacit processes...they may find that they focus on one kind of data....or are predisposed to take predictable kinds of inferential leaps from data."
Rule 5. "Slow down and focus on individuals' emotional reactions; in doing so we can more fully grasp what individuals are up against, as well as how they manage such reactions. The problem is that these reactions are so automatic that we stop attending to them... to publicly retrace and make public these processes involves risks that themselves evoke emotional and defensive reactions that hinder the retrieval of these processes and make it difficult to report them to others." (Argyris, Putnam, et al. 1985 p246-247)

I found it possible to take each of these rules and explore its use in the clinical context. For example, I have already given an example that illustrates the use of rule 1 and rule 5 by inquiring about loss of confidence in the clinical environment. From time to time in the clinic, I would have a visitor, medical student or other doctor, sitting in with me. It was useful to formally ask them to examine one aspect of my clinical style, e.g.

communication and invite them to make comment. Such a process provided an opportunity to look at any difference between my espoused theory (what I thought was happening as I communicated) and my theory in use (developed from inferences that others might have made). Argyris et al believed that attention to action science would eventually lead to a point where the practitioner is able to distinguish his or her own theories in use from espoused theories as part of a reflective practice. Are there ways to encourage reflective experimentation?

According to Argyris, the action scientist does this by becoming 'vulnerable' and by taking seriously any responses that are forthcoming. By vulnerable is meant an inquiry that might proceed along such lines as; "this is my view. I think it's right but I might be wrong, so let's take a look at it." Such an attitude "nurtures a willingness to tell", which will involve risks on the part of the inquirer/ practitioner. This risk is acknowledged by taking seriously what is being expressed. This process is assisted by adopting "a stance toward participant experience that takes account of how they frame what they see, while not taking it for granted." (Argyris, Putnam, et al. 1985 p321-324) Three general requirements must also be met. The interventionalist;

1. Must be able to accurately and usefully comprehend the participants' experience, with some model in his head that will be useful to them.
2. Must have a position of his own that can sustain inquiry, one that can frame errors, difficulties and resistance without triggering protective responses.
3. Agree that not only are mistakes acceptable, they are the raw material of learning and without them the process of inquiry into the theories-in-use would grind to a halt. (ibid)

[The extent to which this has become part of my practice was made clear to me recently. A seven year old boy underwent a tonsillectomy and suffered a disastrous and unexplained post-operative complication that almost resulted in his death. The child eventually made a complete recovery. As we were puzzled by the post-operative course, I suggested to the parents that all the doctors concerned with the case meet up with them to

review what had happened. When this took place it became clear that all was not well because the anaesthetists involved became subjected to a series of questions that became gradually more 'hostile'. In this charged atmosphere, I could see that the anaesthetists were resorting to an explanation of what had happened that was becoming increasingly more technical and sophisticated in biomedical terms and the parents were becoming equally frustrated in asking appropriate searching questions due to their lack of knowledge. I began to wonder if espoused theory was to find out what had happened but theory in use was to explore the possibility of a cover up for a clinical mistake. My response to this situation was to ask the parents if they were asking such questions because they were concerned that a cover up was taking place. The remainder of the discussion concerned itself with this possibility and I had a sense that we had entered a more honest level of inquiry into what had happened. At the end I asked the father if he still felt that we were trying to cover up a clinical mistake and his response was that he no longer felt that this was the case and he suggested that we were to 'free the spirit and move on'.]

There are a number of key questions to address in situations like this where the interventionalist reframes the situation and invites inquiry. The first is the routine one of validity concerning such observations; what are the rules to assist validity? The second is the assumption that eliciting theories in use, particularly if they challenge the espoused theories of the doctor or patient, is necessarily in the patient's interest and if so, who decides? Furthermore, as a researcher, I ask myself how explicit should this process be to the patient? Should it be explicit as good clinical practice (and so much of it seems that way) or should it be explicit as research?

Argyris addresses the question of validity with a set of seven rules that are again summarised below.

Rules to assist **validity**

Rule 1. "Combine advocacy with inquiry....this requires that individuals regard their views as subject to critique and test, it asks that they at once make them public and invite others to inquire into them."

Rule 2. "Illustrate your inferences with relatively directly observable data...when participants make a claim, they provide the data on which it is based."

Rule 3. "Make your reasoning explicit and publicly test for agreement at each inferential step....in the face of conflicting meanings, retrace steps...detect leaps of logic that they and others may make."

Rule 4. "Actively seek disconfirming data and alternative explanations....a common inferential error is to seek confirming data...this strategy may make participants defensive."

Rule 5. "Affirm the making of mistakes in the service of learning....illustrating views, making one's inferences explicit, and seeking disconfirming data all put participants at risk of discovering that they are wrong...it evokes our defences against failure...one way is to regard mistakes as the raw material....doing this is largely contingent on reframing what it means to make mistakes and what it takes to learn."

Rule 6. "Actively inquire into your impact on the learning context...the action scientist wishes to influence the inquiry at hand....this can make mistakes that hinder.....the task is not to diminish the interventionist's influence but to inquire into whether the influence is intended, and whether it is the right influence to exert."

Rule 7. "Design ongoing experiments to test competing views."

(Argyris, Putnam, et al. 1985 p261)

What is noticeable here is the high level of inquiry in the rules that aim to shore up validity. This can be used to address in some measure the concerns one might have about researching practice in a way that involves others without their knowledge. For example, it is possible to inquire about inference in a way that suggests that inquiry into practice is taking place. "What you have said, makes me think that you believe in 'x.' I have become interested in researching the way I practice and I wonder if you would like to comment on my conclusion here." Such inquiry embodies an element of framing in which I

indicate, within the inquiry question, that one role I have here is that of researcher-researcher into my own practice, viz researcher into the medical process. This is not necessarily straightforward for once the frame has been set, subsequent behaviour may proceed in a way that attempt to fit the framing in an effort to make sense of the situation. It seems possible that the act of raising an additional role, that of researcher, may lead to a situation where all my actions may be perceived as those of a researcher into practice and the straightforward role of a doctor is overlooked.

This suggests that attention ought to be directed to 'role' framing. Am I, at any one moment in the clinic, a doctor, a participator, a researcher and how explicit should each of these roles be? The importance of this lies in the fact that this may produce unintended bias on my part that influences data collection. Is what I report (as data) from patients experiences in the medical context contaminated by my role as researcher?

This suggests that threats to the validity of action science may "come from the possibility that participants misreport events.....that the reflection process itself may be sufficiently threatening to provoke individual's defensiveness which may thus increase the likelihood that they will cover up needed information." (Watkins 1988)This means a heavy demand on the interpersonal skills of the researcher. This in turn raises concerns about the question of control. It is possible that many of the techniques described, "with an emphasis on predictable, replicable techniques may inadvertently *encourage* those who would use action science as a gimmick". Such gimmicks may be used to control rather than empower. (ibid)

The Reflective Practitioner

My interest in Schon's work The Reflective Practitioner was stimulated by the title and also by the claim that it offered a new way of understanding how professionals think in practice. It focuses on the professions that operate with uncertain knowledge and conflicting values. It starts by asking provocative questions. "Is professional knowledge adequate to fulfil the espoused purposes of the professions? Is it sufficient to meet the

societal demands which the professions have helped to create?" It talks about a 'crisis of confidence' that has arisen from "questioning professionals rights and freedoms" which has led to deeper questioning of the professional's claim to extraordinary knowledge in matters of human importance. This has been developed by some to show how professionals "misappropriate knowledge in their own interests and the interest of a power elite intent on preserving its dominance." (Schon 1983 p13)

This situation has partly arisen because of the "complexity, uncertainty, instability, uniqueness, and value conflicts which are increasingly perceived as central to the world of professional practice. In such fields as medicine, professionals speak of a new awareness of complexity which resists the skills and techniques of traditional expertise. As physicians have turned their attention from traditional images of medical practice to the predicament of the larger healthcare system, they have come to see the larger system as a 'tangled web' that traditional medical knowledge and skill cannot untangle." (ibid) As a consequence the situations of practice are seen as unique events and an eminent physician has claimed that "85 percent of the problems a doctor sees in his office are not in the book'." (ibid) This new found awareness has led to the development, in some areas, of professional pluralism. In medicine, attempts are currently being made to resist such pluralism by the development of restrictions to practice seen in treatment algorithms and evidence based practice. An indirect consequence of this may be the rapid expansion of 'complimentary' medical practices such as acupuncture and homeopathy as an alternative pathway to pluralism. Incidentally, the use of the word 'complimentary' in complimentary medicine is interesting because it suggests an alignment with conventional medicine but as conventional medicine strives to distance itself from such activities by it's emphasis on *evidence* as a basis for treatment, this relationship may change.

The principal problem lies then in the mismatch in applying "traditional patterns of practice and knowledge to features of the practice situation, of whose importance they are becoming increasingly aware." (Schon 1983 p18) Nevertheless, Schon assumes that competencies do exist but what is missing is an epistemology of practice that begins to

describe or explain such competencies. Such competencies can only be explored, according to Schon, by the specialist themselves "for who, other than another similarly qualified specialist, can challenge him?" (Schon 1983 p7) This simple assertion is, as I see it, the keystone upon which the whole approach depends and remains probably the most significant difference from the action science of Argyris, who portrayed the interventionalist as the facilitator to understanding.

What is particular about the epistemology of professional practice? The systematic knowledge base of a profession is thought to have four essential properties. It is "specialized, firmly bound, scientific, and standardized." (ibid) Schon held the view that this last point was particularly important because professionals are led to believe that the paradigm in which the profession knowledge is developed, should also form the paradigm of practice. In practice, he believed, this is achieved by applying standardized knowledge, in the form of very general principles, to concrete situations. This concept of 'application' leads to a view of "professional knowledge as a hierarchy in which 'general principles' occupy the highest level and 'concrete problem solving' the lowest." (ibid) To assist this analysis, Schon draws upon the work of Edgar Schein who described three components to professional knowledge:

1. An underlying discipline or basic science.
2. An applied science or engineering component applied to day to day diagnostic procedures and problem solving.
3. A skills and attitudinal component that concerns the actual performance of services to the client.

(Schon 1983 p24)

This hierarchical separation of research and practice, he called 'technical rationality'. This model is reflected "in the institutionalized context of professional life, in the institutionalized relations of research and practice and in the normative curricula of professional education. Even when practitioners, educators, and researchers question the model of technical rationality, they are party to institutions that perpetuate it." (Schon

1983 p26) This is seen particularly well in the manner in which the curriculum of a medical school is developed, where the order of the curriculum reflects the underlying components of medical practice, a relationship I have indicated in the opening sections of this thesis. The first few years are spent developing a basic science approach to medicine, emphasising the positivist's aspects of medicine. Then on the wards as a student, an applied science is developed and finally, after qualification, the skills to be able to apply this knowledge in context are developed. It should be noted that the teachers in each of these aspects are different. The hierarchy of high level basic science to low level application is embedded in the training system.

The problem with a hierarchy of knowledge founded upon a positivist paradigm is that it can find no place for practice, for practical knowledge. The assumptions of positivism do spread seamlessly from basic science to practice. As previously mentioned "practice appears as a puzzling anomaly" until it is construed as "the relationship of means to ends. Given agreement about ends, the question, "How ought I to act?" could be reduced to a merely instrumental question about the means best suited to achieve one's ends." With this emphasis on problem solving, the problem *setting* could be ignored as much or a little as one wished for "problem setting is a process in which, interactively, we *name* the things to which we will attend and *frame* the context in which we will attend to them." (Schon 1983 p21-75) In professional practice it is possible then to decide what components of the setting are to be regarded as important and this forms the frame of the problem to be solved. Perhaps the variation of possible problem settings can best be seen in the career choices that are possible in medicine.

"In such 'major' professions as medicine, there are zones where practitioners can function as technical experts. But there are also zones where the major professions resemble minor ones. There are those who chose the swampy lowlands. They deliberately involve themselves in messy but crucially important problems and, when asked to describe their methods of inquiry, they speak of experience, trial and error, intuition, and muddling through. Other professionals opt for the high ground. Hungry for technical rigor, devoted to an image of solid professional competence, they choose to confine themselves to a

narrow technical practice." (Schon 1983 p42-43) This has been described as the choice between 'rigor or relevance'. In an earlier part of the thesis, when I was phenomenonologically inquiring into career choices, I drew up a list of career possibilities that highlighted this choice. It could be seen that in some branches of medicine it may be possible to pursue a career with an emphasis on rigor, such as in biochemistry and in others an emphasis is placed on relevance, such as in general practice. Such an approach can be seen as selective inattention to data. What happens when, as a practitioner, one wishes to practice with rigor *and* relevance? In such a situation, technical rationality has limitations and it may not be possible to fill the gap between a positivist knowledge base and practice.

Schon tries to answer this by recognising that when the professional acts in a certain way, he or she might start to ask questions about this process. He proposed a methodology to undertake this in a systematic manner and the central pillar of this approach he called 'reflection in action.' He starts by observing that; "every competent practitioner can recognize phenomena, for which he cannot give a reasonably accurate or complete description. Even when he makes conscious use of research based theories and techniques, he is dependent on tacit recognitions, judgements, and skilful performances. Professional people often think about what they are doing, sometimes even when they are doing it, they may ask themselves. 'What features do I notice when I recognize this thing? What are the criteria by which I make this judgement? What procedures am I enacting when I perform this skill? How am I framing the problem when I perform this skill? It is this entire process of reflection-in-action which is central to the art by which practitioners sometimes deal well with situations of uncertainty, instability, uniqueness and value conflict."(Schon 1983p49-50)

Reflection in action is linked to the concept of 'knowing in action.' Using the argument of 'common sense' Schon admits a category of 'know-how' and that knowing in action is nothing more than 'know how' *in* the action. As a researcher I note that what he calls 'common sense' is nothing of the sort. The manner in which he constructs his argument is a skilful application of practice. It is an academic 'know how' and is no different in

essence from the phenomenon he is attempting to describe. He is thus using a methodology (reflection in action) to elucidate an epistemology (practice) to be applied to the same methodology (reflection in action). At one level it can be construed as a tautological, self referencing argument. However, he goes on to note a number of properties associated with this concept of practical know how.

1.There are actions, recognitions, and judgements which we know how to carry out spontaneously; we do not have to think about them prior to performance.
2. We are often unaware of having learned to do these things; we simply find ourselves doing them.
3. In some cases, we were once aware of the understandings that were subsequently internalized in our feeling for the stuff of action. In other cases, we were never aware of them. In both cases we were usually unable to describe the knowing which our action reveals.
(Schon 1983 p54)

He completes the argument by arguing that if we 'know in action' then we can observe ourselves knowing in action, and this is the phenomenon of 'reflection in action'. He takes as an example the 'sense making' that jazz musicians makes as they reflect on the music they are collectively making. (Schon 1983 p55-56) Much reflection in action hinges "on the element of surprise." When experiences are encountered that are pleasing or otherwise, the practitioner may respond by reflecting in action.

The methodology is completed by attention to two key features; the process of framing and experimentation. In methodological terms, framing and experimentation, results in a sequence of events described by Schon as *exploration, move testing, hypothesis testing* and *evaluation of outcomes.*

Exploration, or 'exploratory experiment', is a "probing playful activity by which we get a feel for things. It succeeds when it leads to the discovery of something else." (Schon 1983 p145) It is a process of reframing a problem, which usually in itself suggests a direction

for reshaping the situation. The second stage of move testing, is an action taken in order to produce intended change. The third stage of hypothesis testing "consist of moves that change the phenomena to make the hypothesis fit. The inquirers influence the unique situation at hand, the domain of inquiry. They influence the totality of their object of study and seek to exert influence in such a way as to confirm, not refute, their hypothesis." This is a process whereby the practitioner tries to make the situation fit the frame but in doing so must remain open to the possibility that this may not be possible. Attention must be focussed particularly on those aspects that are resistant to change. An analysis of consequences usually takes on the following form.

Consequences in relation to intention	**Desirability of all perceived consequences, intended or unintended**
1. Surprise	Undesirable
2. Surprise	Desirable or neutral
3. No surprise	Desirable or neutral
4. No surprise	Undesirable"

(Schon 1983p152-153)

This approach differs from that of Argyris in a number of ways. Schon places a much greater emphasis on the process of framing. In the process of asking the question Why is this so? Argyris would imply an action that suggests change for the better. Schon reframes a problem in such a way that suggests a direction for reshaping the situation but leaves open the possibility that it may not be 'for the better'. Schon seems to adopt a more neutral view by arguing that the outcomes that emerge from this reframing, shed light on the understandings that shape the phenomenon. In professional practice, this process of reframing is particularly triggered by becoming 'stuck' in a problem and leads to what he calls a 'frame experiment'. However, the repetitive nature of professional practice, is such that professionals encounter certain situation again and again. This "confers on him and his clients the benefits of specialisation" but also leads to a

narrowness of vision as well as an increasingly automatic response to certain situations. (Schon 1983 p60-61)

The 'narrowness of vision' developed as a result of specialisation raise two points concerning becoming 'stuck' and the opportunity for surprise. Firstly, as one becomes more experienced, the opportunities to become stuck, which leads to reframing, are likely to be reduced. How does the practitioner keep up the element of surprise? Secondly, and perhaps more importantly, however, the perceived way of looking at events is continually reinforced as the correct way of doing do. Opportunities for reframing remain dependent upon continually taking seriously the "uniqueness of the present situation" and not becoming lulled in a sense of familiarity generated by repetition. My whole thesis rests upon the idea that I have reframed my practice *despite* my experience and I would be the first to admit that outside stimuli and input have been obligatory in generating such change. I could not have attempted this from within the confines of my own practice and with the aid of 'The Reflective Practitioner'-something else must have taken place. I believe this to have been the input of others, family, patients, colleagues, fellow students, supervisors and examiners. Whilst the methodology of reflective practice does not exclude an input from these parties, the onus remains upon the practitioner to generate new frame experiments to trigger new understandings.

With this in mind, how does Schon approach the question of validating such an approach? This is approached firstly by judging the reframing in terms of a set of questions.

Can I solve the problem I have set?
Do I like what I get when I solve this problem?
Have I made the situation coherent?
Have I made it congruent with my fundamental values and theories?
Have I kept inquiry moving?"
(Schon 1983 p133)

"The practitioner evaluates his problem-setting experiment by determining whether he likes these unintended changes, or likes what he can make of them. The practitioner (may) value the unintended changes he has made or discovered. The evaluation of the frame experiment is grounded in the practitioner's appreciative system, he judges a problem-setting by the quality and direction of the reflective conversation to which it leads. This judgement rests, at least in part, on his perception of potentials for coherence and congruence which he can realize through his further inquiry." (Schon 1983 p135)

These questions and evaluations, used to judge quality, depend upon Schon's opening assertion that only the professional is in a position to judge his or her practice because they remain the only person in a position to validate such practice. As a researcher, I ask myself what it is one is trying to do here? If the idea is to produce a methodology of practice for the professional, then self referencing evaluative criteria like these may be acceptable, because if nothing else they will encourage a process of critical evaluation of practice. As well as being attractive to a professional used to maintaining independence of action, this approach to quality may be better than none at all. As a foundation for a critical theory methodology, such self-reflective validation on its own may not be a sustainable position. This is seen at a later stage when Schon applies the ideas to a particular problem and offers the following values as a means of developing quality.

1. Give and get valid information
2. Seek out and provide others with directly observable data and correct reports, so that valid attributions can be made
3. Create the conditions for free and informed choice
4. Try to create, for oneself and for others, awareness of the values at stake in decision, awareness of the limits of one's capacities, and awareness of the zones of experience free of defence mechanisms beyond one's control
5. Increase the likelihood of internal commitment to decisions made
6. Try to create conditions, for oneself and for others, in which the individual is committed to an action because it is intrinsically satisfying, not because it is accompanied by external rewards and punishment.

7. Make protection of self or other a joint operation, so that one does not withold negative information from the other without testing the attribution that underlies the decision to withold.
8. Speak in directly observable categories, provide the data from which one's inferences are drawn and thereby opening them to discomfirmation.
9. Surface private dilemmas, so as to encourage public testing of the assumptions on which such dilemmas depend.
(Schon 1983 p231-232)

These criteria, not in many ways different from the openness advocated by Argyris (and also by Torbert) represent an attempt to increase the degree of *reflexivity* which is not generally evident in reflection in action as far as agenda setting and move testing is concerned. Such a position has raised questions about the level of participation by various members. This research method has been viewed as essentially "phenomenological, in that it focuses on the subjective processes of interpretation that a reflective practitioner applies in working through a problem. "(deNeufville 1984)

As a researcher, I am left with the impression that whilst it offers a method that generates insights into practice, by itself it, would be insufficient as a methodology for research into clinical practice. What I feel is missing is an awareness of ontological position as a researcher, in order to ask questions about the significance of quantitative and qualitative data encountered in the clinical interaction. Hence, my model outlined at the beginning is based upon an appreciation of the shortcomings of solely adhering to this approach. This conceptual model is reproduced here for reference.

1. In my position as a doctor I operate at one level as a positivist (positivist theory generating data production).
2. At the same time I have tried to work as a reflective practitioner/ action inquirer (constructivist theory underlying nature of data and data production)

3. And finally as a researcher I try to develop an awareness of the ontological position I am adopting. This may be described as theory behind theory in that it represents an awareness of the assumptions circumscribing a particular paradigmatic position.

Action Inquiry -Torbert

I was attracted to the idea of exploring the book The Power of Balance; transforming Self, Society and Scientific Inquiry (Torbert 1991) by the man himself. I first met William Torbert in September 1994 when he was a facilitator in a three day conference at Hawkwood, England. One reviewer suggested that the book contains "a great deal of male discourse and deliberation. His closest confidantes and co-conspirators over the years seem to be male. The most prominent female figures in the book seem to involve wives and lovers, who represent pain/ ecstasy in his life." (Mitchell 1993) This book had fairly clearly portrayed his position in society (as a white middle class professional male) a position that is normally well defended and yet he had, through his openness, expressed a certain vulnerability. For these and possibly other reasons, he was robustly criticised on a number of occasions during the conference and on one occasion this was sufficiently hostile to apparently move him to tears. What impressed me was that even in the face of this hostility, he appeared to be still able to listen to the messages behind the rhetoric and maintain his openness. Here appeared to be someone who could practise what he wrote about in his book in a manner that I saw as convincing. "The intellectual power of balance.....includes the intellectual capacity to think on one's feet in the midst of crisis....moral capacity to act with integrity and compassion in times of pressure....the strategic capacity to weave all that one knows...into actions that reverberate positively an *all* time horizons, the visionary capacity to see what one does not see and to challenge the assumptions of one's current way of seeing and thinking, to see other perspectives and to see through transformations in one's own perspective."
(Torbert 1991 p5)

The book claims "to present a new theory of power, a new practice of management, and a new approach to conducting social science" which as one review comments "is no mean achievement for any author". (Cooper 1991) His vision of action 'inquiry', a term Torbert employs to distinguish it from action research and action science, is based around an "attention that spans the four territories of human experience", derived from Plato.

Intuitive mission
Rational strategy
Behavioural operations
Tangible outcome
(Torbert 1991 p35)

"This attention is what sees, embraces, and corrects incongrueties among mission, strategy, operations, and outcomes." This type of action inquiry goes beyond professional boundaries and is "*a kind of scientific inquiry that is conducted in everyday life. It is a kind of social science that deals primarily with 'primary' data encountered 'on-line' in the midst of perception and action*" and only secondarily with secondary, or instrumental data, "collected and analyzed 'off-line'." Such "*consciousness in the midst of action...is both the ultimate aim and the primary research instrument in action inquiry.*" (author's italics) (Torbert 1991 p219)

Coupled with this awareness is the need for a transforming leadership, which is what particularly distinguishes Torbert's version of action science from that of Argyris and Schon. This transforming leadership is a "blend of four types of power, unilateral power diplomatic power, logistical power and transforming power". (Torbert 1991 p13-32) The *ability* to exercise and appropriately blend these four different types of power he called 'the power of balance.'He develops a hierarchy of leadership qualities reflecting the various ways that such power can be exercised.

Governing frames at successive developmental stages

Stage	*Name*	*Governing Frame*
1	Impulsive	Impluses rule reflexes
2	Opportunist	Needs, interests rule impulses
3	Diplomat	Expectations rule interests
4	Technician	Internal craft logic rules expectations
5	Achiever	System success in environment rules craft logics
6	Strategist	Principle rules system
7	Magician	Process (interplay of principle/action) awareness rules principle.
8	Ironist	Intersystemic development awareness rules process

"Each succeeding construction 'dethrones' the assumptions of the previous construction and transforms them from their role of framing and governing reality to a new role as variables within a wider reality." (Torbert 1991 p42-43) This power is most appropriately exercised through the use of 'liberating structures', which are "paradoxical structures that shape a subordinate's efforts while at the same time also stimulate a leader's self questioning and authentic action." (Marshall 1992) This developmental management theory has been criticised on the grounds that one "can only appreciate those meanings at one's own stage of development or below." This can make it all too easy for those at a higher stage to devalue those at a lower stage. (Putnam 1993)

Action inquiry is individual inquiry with the aim of collaboration. If this is successfully managed it may lead to a 'community of inquiry'. It is this feature particularly, that Torbert saw as the distinguishing feature that separated his work from that of Argyris. He maintained that action science, whilst claiming to "seek to enact communities of inquiry in communities of social practice" overlooked three important considerations. Firstly, "how far communities of practice in the everyday world diverge from the ideal of community of inquiry. Secondly, how far the community of scientists themselves diverge from the community of inquiry and finally how far the current scientific ideal of a community of inquiry diverges from an ideal that can resolve paradigm disputes and be realized in communities of practice." (Torbert 1991 p239-240) He takes the view that Argyris and his colleagues appear to assume that "the distance in all cases is relatively small, one of degree not of kind." (ibid) Argyris, he goes on to say "implies that science

has something to offer practice but not vice versa", a position, incidently, that Schon also attempts to correct. Furthermore, the assumption that "the apparently small distance between mainstream scientific values and action science values is in fact the case, an assumption not borne out by a) reflection and b) the "lack of conversation between empirical scientists and phenomenologists." Finally, he argues, "Kuhnian analysis highlights how scientific communities as communities of social practice are unable to resolve paradigm disputes." (ibid) By resolving these, he proposes a "new kind of social science, management, teaching and learning aiming at creating communities of inquiry (peer cultures) within communities of social practice." In this respect he feels that Argyris has fallen short of creating a community of inquiry. (ibid)

If the methodology is different, then it may be useful to examine how is data generated using this model and how is it tested? First of all Torbert advocates that relevant data is generated not just in our professional lives, but also in our personal lives as well. "Good practice should not be reserved just for our professional lives." (Torbert 1991 p222) This approach led one sympathetic viewer to comment that it "challenges perceptions about appropriate boundaries, and it reunites productivity and inquiry, reason and feelings, the professional and the personal. The detached view of scientists as observers, who often lead lives uninformed by their own theoretical insights, seems inappropriate as we move into the complexities of the post-modern age." (Marshall 1992) This approach, where action inquiry is seen as a "a dialectical, experiential process that treats the four territories of experience as distinct-vision, strategy (reasoned or felt), action, and the outside world- and that seeks to enact congruent patterns across all four territories of experience" is very demanding upon the inquirer. Data is likely to emerge from every direction and this may be difficult to hold so that "even if we widen our awareness momentarily in response to some reminder, it narrows again very soon, and we do not feel its narrowness." (Torbert 1991 p222) In everyday experience, knowledge may be perceived as adequate until one becomes aware, and this has to be an intentional process conducted *in the present,* of the four territories of experience. This reminds us of the "narrow cognitive interpretive net we apply to our perceptions. We are rarely aware of our own behaviour and others' reactions as we act." (ibid) (I found that this was personally illustrated to me when I saw

myself on video for the first time) This action, in which we "verify for our selves the four territories of experience" then permits a widening of the scope "of alternative actions and strategies." (Torbert 1991 p228) This suggests fairly intensive data analysis which would be generated for several years whilst undertaking a thesis.

Since talk forms that principle basis of action, communication and the way we conduct it is important. Communication "in daily, professional, and intimate conversations can be understood and practised as efforts to communicate in all four territories of experience." (Torbert 1991 p233-234) This suggests a method that can be employed that pays attention to the four parts of speech.

1. *Frame*- the assumptions that bound conversation, the "name of the game", the purpose of speaking;
2. *Advocacy*- a particular goal to be achieved, an abstract assertion about perception or action;
3. *Illustration*-a concrete example, a colourful story; and
4. *inquiry*- an invitation to respond, an effort to determine the effects of one's action (one's speaking) or others perspectives on the matter.(ibid)

The approach to framing was reflected in my research both as a reflective practitioner and as a researcher. As a reflective practitioner I would pay attention to the framing process of the clinical problem but do so with what I perceived as a greater level of clarity than before. For example, it appears to be a common occurrence for patients to perceive a specialist as knowledgeable about clinical problems outside their area of expertise. This phenomenon was illustrated by a patient, who came to the clinic with a nasal problem, but instead sought my opinion about treatment she had been given for her asthma. I was happy to discuss her nasal problem but did not feel equipped to discuss her asthma treatment. The framing process commenced by clearly delineating my area of expertise, and having done so, negotiated, through inquiry, agreement about the goals to be achieved by the consultation. This process was noticeable enough to elicit comment from another doctor sitting in the clinic with me. Framing the problem as a researcher means

paying attention to the theory frame or paradigm in which the medical discourse is going to take place. Will it be appropriate to be positivist or constructivist here and how do I validate this position?

Torbert's communication strategy also suggests a higher level of inquiry at each of the stages of framing, advocating, illustrating and inquiry. There is a level of inquiry implicit in the framing process because it is perceived as a set of assumptions in the first place. The illustrative phase of the process is seen as a further level of inquiry by offering an example to check out the clarity of the assertion to the other participant. Finally, the inquiry process at the end is to invite feedback before a process of reframing starts the cycle again. Torbert saw this as a "process to invite the exercise of mutual influence and transforming power, while increasing the validity of the data available about how participants are experiencing the situation." (Torbert 1991 p234)

However, much of his approach has been criticised as "too normative and too idealistic" to be as useful in practice as perhaps it should be.(Bird 1993) There is no reference to the everyday dynamics of race, gender and class, a particular concern because of the privileged position of the white, middle class professional male in western organisations.(Mitchell 1993) Nevertheless, Torbert's vision of action inquiry more overtly acknowledges the existence of communities of inquiry, emphasises the importance of inquiry in both framing and advocating and develops a case for connecting leadership more fully with the process of inquiry. In many ways, this conveniently leads to the final version of action inquiry, participative action inquiry.

Co-operative Inquiry

Action research in the participatory paradigm is characterised by a form of research more usually called co-operative inquiry. The first formal account of co-operative inquiry, or as it was then called 'experiential research', was published in 1971 by John Heron. He drew attention to an inconsistency in conventional psychological research when an original researcher "assumes a free autonomous cause in their own behaviour....and at the same

time denies its relevance to the behaviour of their subjects, for example explaining their subjects' behaviour in terms of strict causal determinism?" And conceived the idea that the "researcher is necessarily also the inquiring agent, who is both experimenter and subject combined." (Heron J. p3, 1996).

The main emphasis in co-operative inquiry is on research *with* people not research *on* them or *about* them. In this respect each member of a co-operative inquiry group is a co-researcher, co-subject and participant. The very words 'co-operative inquiry' suggest a level of mutuality missing from many other forms of research both qualitative and otherwise. The defining features of this approach have recently been summarised:

1. *All* subjects are as fully involved as possible in *all* research decisions taken in the reflection phase
2. There is an intentional cycling between reflection and sense making with experience and action
3. Explicit attention is paid to validity procedures
4. A radical epistemology is developed that is both informative and transformative
5. There is a need for a range of special inquiry skills
6. Use of the full range of human sensibilities should be considered

(Heron J. p36,1996)

The radical nature of the extended epistemology is seen particularly in the four main inquiry outcomes, "which correspond to the four forms of knowing: experiential, presentational, propositional and practical" (ibid). In this respect the full range of human expression is regarded as legitimate. These include transformations of person (experiential) and presentations of insight through "dance, drawing, drama and all other expressive modes, which provide imaginative symbols of the significant patterns in our realities." (Heron J. p37,1996). Heron (ibid) perceived some of these inquiries as transformative, including for example transformation of the environment, social practices, self-directed learning, intimacy and others, others are perceived as informative.

Transformative inquiries are seen as a result of developing particular practical skills, which are seen as exercising primacy over reports or presentational insights.

Whilst the intention might be to encourage full participation in all research decisions, which is one particular hallmark of co-operative inquiry, such a radical epistemology is not likely to give rise to a uniform style of inquiry. Indeed there are a number of different types of inquiry as outlined by Heron. (Heron 1996 p40-42) These may be 'bootstrap'; internally or externally initiated; full or partial forms; same, reciprocal, counterpartal or mixed role. The bootstrap inquiry group chooses to be entirely self-initiating by either reading how to do it, or experimenting to find its own way to approach an inquiry. In internal inquiry groups, the initiating researchers are "personally engaged with the culture or practice which the research is about," whereas in the external group, the initiating researchers are externally placed. In full form inquiry groups, every participant is fully involved as both co-researcher and co-subject, but in partial forms the initiators may only be involved as co-subjects. 'Same' 'reciprocal', 'counterpartal' or 'mixed role' are to do with "inquiries that focus on practice within a given social role. In 'same' inquiry models, all co-inquirers have the same role. 'Reciprocal' is the name given to inquiries in which co-inquirers have roles of equal status, for example a spouse, partner or colleague. Counterpartal role inquiries are ones in which co-inquirers include a sample of all the kinds of participants likely to be encountered in an inquiry into that phenomenon. For example a group interested in the practitioner client relationship might include doctors, nurses, patients, families. Finally, a mixed role includes different kinds of practitioner, for example different therapists such as general practitioners and complimentary therapists.

An inquiry may be started by an initiator's call, in which an individual launches an inquiry by forming, with appropriate publicity, an inquiry group interested in exploring a specified topic. This is the usual manner in which a group will form. Data generation is made by undertaking a series of research cycles. These move through four distinct stages of;

- Reflection
- Action
- Full immersion
- Reflection and planning for further action

The first reflection phase may decide on a number of alternatives; a more focused topic for research, a plan for the first action phase, consider a method of recording data during an action phase. The action phase, in which each participant is both co-researcher and co-subject, will explore a particular experience related to the inquiry topic, apply an inquiry skill or make a record of experiential data gained. The full immersion phase may be characterised by a new awareness or breakthrough to a 'new perception'. Finally the second reflection phase will usually attempt sense making with a view to redefining the inquiry topic, but may also review the method of data recording or modify the plan for the next cycle. (Heron 1996 p50).

Heron has identified two distinct styles of co-operative inquiry culture, which he has termed Apollonian and Dionysian. The Apollonian inquiry "takes a more rational, linear, systematic, controlling and explicit approach to the process of cycling between reflection and action." The sequential steps are rational; "plan, act, observe and reflect, then re-plan." The Dionysian inquiry takes on " a more imaginal, expressive, spiralling, diffuse, impromptu and tacit approach to the interplay between making sense and action." In the reflection stage they "share improvisatory, imaginative" ways of making sense and the implications for this are not worked out by rational pre-planning. In their own way, both share an "intentional interplay between making sense and action." (Heron 1996 p45-47)

Heron maintained that such a methodology called for special inquiry skills and validity procedures. Special inquiry skills regarded as useful for informative inquiries have been termed 'being present'; 'imaginal openness'; 'bracketing'; 'reframing'. These inquiry skills are to do with empathy (being present), being "receptive to the meaning inherent in the total process of shaping people" (imaginal openness), managing conceptual labels "embedded in the perceived world", to be more open to "inherent, primary, imaginal

meaning (bracketing), and being "open to reframing the assumptions of any conceptual context or perspective (reframing)." (Heron 1996 p58-59) I notice that all these special inquiry skills have one thing in common, the ability to return to data, to overlook the cultural inference we make about people, statements and talk and to disregard constructively the classifications we make about what we see. Such a return to data, to the basic experience, opens up the possibility of new associations or new relationships. The early part of this thesis indicated that I had come to recognise that the way I had been looking at the world was dependent upon adopting a set of assumptions that allowed me to make sense of data. This was proving to be problematic as I strove to add complexity and understanding to an analysis of the clinical situation. The attraction of co-operative inquiry methodologies, in their full participative mode, was that it encouraged a co-inquirer to return to basic data in the form of basic experience and to re-evaluate the classifications that had formed part of one's cognitive and practical makeup since birth. It encouraged one to reclassify what had been discarded or ignored to be useful, informative and such reframing encouraged the researcher to make new sense.

Inquiry skills that relate to 'radical' practice have been termed 'dynamic congruence'; 'emotional competence'; 'non-attachment'; and 'self-transcending intentionality'. These have been described in the following way; "practical knowing, or knowing how to act" (dynamic congruence); "the ability to identify and manage emotional states in various ways" (emotional competence); the "ability to wear lightly and without fixation the purpose, strategy, form of behaviour and motive which have been chosen as the form of action" (non-attachment); and the "skill of having in mind, while busy with one form of action, one or more alternative forms" (self-transcending intentionality). (Heron J. 1996 p58-59)

Such a methodology calls for special validity procedures, whose purpose is to "free the various forms of knowing involved in the inquiry process from the distortion of uncritical subjectivity." (ibid) This approach to validity is consistent with an epistemology that accepts almost any form of experience as legitimate for inquiry, and utilises special inquiry skills that challenge conventional emotional responses, conventional

classifications of experience, typical responses and intellectual fixedness. In a sense the purpose of validity is to challenge any aspect of the research that has perceived structure or appears to be resistant to change. Given such a requirement, validity is therefore often seen as a balance between opposites, no one polarity gaining dominance over the other. A balance is therefore required between "divergence and convergence within the action phases of one or many research cycles".(ibid) Several cycles of action and reflection reinforce the notion that the inquiry topic is not subject to organisation and fixedness-it is an indication that engagement is sufficient. A balance between reflection and action suggests a harmony between mind/body perception. Challenging uncritical subjectivity is an agreement that any inquirer can be authorised to act as 'devils advocate' in order to "question the group whether one or several forms of critical subjectivity is afoot."(ibid) A perceived "interdependence" between chaos and order suggest an "attitude that tolerates and undergoes, without premature closure, inquiry phases which are confused and disorientated, ambiguous and uncertain, conflicted and inharmonious, generally lost and groping." (ibid) It is necessary to adopt some regular method of "managing unaware projections of some past or emotionally repressed traumas" (ibid) and finally looks for evidence of genuine, authentic collaboration.

So far I have discussed the various ontological positions to adopt as a researcher and considered what constitutes data within the positivist, post positivist, critical theory, constructivist and participatory paradigms. This has included a discussion on how data is generated in each of these paradigms, particularly with a view to generating data that was relevant to professional practice. I have also considered various research questions and underpinning all research questions is the need to ask *relevant* questions. This has been followed by a careful review of some of the methodologies available to a qualitative researcher. The resubmission has enabled me to indicate how I found some of these methodologies useful in generating data. I have concluded that an action research methodology is appropriate because of the need to ask *relevant* questions *in the moment.*

The third section of the methodology sections;

1. Ontological and epistemological issues in relation to a research question

2. Linking research questions, epistemology and methods

3. Ethics, morality and politics of the research process

4. Producing a practical research design

devotes itself to the ethical problems of undertaking clinical research of this kind before putting together what I perceived as a practical research design in the final section.

Section 3

Ethics, morality and politics in research design

In relation to developing an ethical research practice I would like to address five particular problems. Firstly, there are problems in determining what is meant by 'research' when it becomes inextricably linked with practice. Secondly, there are problems in separating out implicit from explicit permissions to undertake 'research'. Thirdly, there are problems in adopting a particular ethical research stance. Fourthly there are problems in understanding at a moral philosophical level what is right and what is wrong and fifthly there are problems in trying to make sense of it all and adopt a position that aligns with common sense.

How do I determine what is research when it is linked to practice? In the clinical interaction there are a number of activities taking place, some or all of which may be regarded in one sense as 'research'. Firstly, there is the investigation of the clinical problem. It is a kind of research or investigation into natural phenomena. Then there is the research into clinical practice, the attempt that I make as a doctor to try and become a better one. Finally there is the research, depicted in this thesis as 'a researcher', in which I ask myself questions about the theory behind the theory behind the data. This is the process through which I attempt to make sense of context, context of phenomenon, context of data, context of theory. At one level all of these different processes constitute research and each should have a particular ethical position but at another level they would appear to be the constituents of good practice. For which of these levels of research is it necessary to obtain permission to research?

This is what I mean by the problem of separating out implicit from explicit permissions to research. I have made the assumption that any patient who comes to the clinic has given implicit permission, to a certain level at least, that they wish me to investigate/ research the clinical problem. Furthermore, I have made the assumption that any patient who comes would wish me to adopt a 'research' stance on such clinical practice that is

aimed at improving that clinical practice and that they are necessarily part of one's process. It could be argued that these are unethical assumptions to make, that each clinical consultation should start with a explanation that research is about to take place and the ethical position of that research should be clarified. The impracticality of this approach means that it doesn't happen most of the time, but on specific occasions it does. When patients are asked to become part of a clinical trial of treatment, then the clinical process as 'research' has to be transparent. There are also other moments when I, as a doctor, am aware that my treatment has an element that is essentially experiment. For example, neither the parent nor myself is usually very certain what effect a persistent hearing loss in a small child has had on behaviour. In suggesting a treatment that would restore hearing to normal, I am not certain of the outcome on behaviour. In this respect the surgery constitutes an 'experiment', and I try to make this position clear. In everyday terms, however, permission to investigate a clinical problem is accepted as implied and I take this to be reasonable. Is it safe to assume the same permission as 'researcher', in which I trying to look at myself and the patient, has been granted and which would appear to be beyond what a patient might expect as part of a clinical consultation?

Denzin and Lincoln have identified five ethical stances in research; the absolutist, the deception model, the relativist stance, the contextualized-consequentialist model and the feminist position. (Denzin & Lincoln 1994 p19-22) The absolutist "argues that social scientists have no right to invade the privacy of others" and regard "disguised research as unethical." Such a model dictates that my position as a researcher should be made clear. For some of the time this is straightforward and at other times it is not. When I have undertaken interviews about my practice, when I am interviewing patients about the problems of decision making, the early part of the interview is devoted to trying to obtain permission on this point. The very act of obtaining this permission may well allow an agenda of the other party to emerge, so that adopting an overt ethical stance as a researcher may well influence the data generation.

In my conversation with Valerie (appendix 3) the process of obtaining ethical permission to proceed as a researcher ran into problems. We had agreed to meet and talk about her

difficulty in deciding whether to accept a heart/ lung transplant. This part of the conversation took place at the beginning of the interview.

R: You, you've asked me to have a little discussion at the beginning about what it is that I'm trying to do. That's why I'm going to start, start off by talking. I think we were going to also learn from this about what it is that you would like to get out of our chat because you, you have an interest in talking about this as well?

V: Mmm.

R: as well and, I, I will also address the question of confidentiality on video and if, if, if it turns out that things are unacceptable

V: Mmm.

R: you can always switch it off or

V: Yes.

R: either at the beginning, middle or end or at a later stage. I, as you know, work as a doctor. I work within a medical framework in which I obtain medical information and try and advise in the most appropriate sense. What I'm, have been interested in looking at is what people do when doctors and patients with information that may be not medical in the strictest sense of the word, but maybe important in terms of determining what they do. And that involves trying to decide if, if that happens and if it happens what are the circumstances that bring this kind of evidence into the discussion. Do doctors permit patients to bring this in? Do they restrict access in all kinds of ways? Does the whole business of being, being in a conventional western framework of medicine make it very difficult for patients to make decisions. That involves looking very much at myself and how I handle this. What do I do with this information? Do I disregard it? Do I pay attention to it? Do I pay lip service to it? Do I, do I pretend to pay attention to it? But all the time underneath it, ignoring it but in a more subtle way. That sort of thing, but also asking patients how they construct images of their own illnesses and how they apply medical information in the conventional medical sense in terms of making the decision themselves. Is that clear? Is it?

V: Yes, that's fine.

R: Good. So, we are going to begin this well actually perhaps the best thing to do would be to

V: You're talking about it particularly within the realms of decision making?

R: I suppose so. That, that is the point at which a decision is made that, that forms the, the focus for, for thinking about these issues but of course these issues enter into a clinical context at all times without necessarily a decision being made. And yourself, what would you like to get out of this discussion?

V: I don't know. I am very interested in an area which I think the National Health is beginning to address and that is what the patient themselves is happy with in terms of treatment even though that may not always be the best in terms of whatever clinical measurement is available. That which might make the patient feel much happier and, in doing so, would allow them to relax and be more receptive to what ever treatment they do have and may end up perhaps producing a better result or perhaps in the patient having a better quality of life in their own terms.

R: mmm,

V: that's part of it.

R: OK.

V: And the other part of it I think is the, the awe in which the medical profession is still held by people generally, most of all by patients, prevents many people from feeling that they can address issues about their treatment with their doctors; indeed they rarely have the information to do so. The language of the medical profession is very technical and specialised, whereas the concerns of patients are usually voiced very much in terms of their feelings, intuition and fear of consequences. In addition fear of the unknown plays a large part in a patient's comfort and it is rare for this to be dealt with in a supportive way by staff without underestimating a patient's ability to understand what is going on. Patient's fears or enquiries are likely to be addressed to the staff, who are readily accessible to them, the less qualified grades of nursing staff. Although these nurses are often most sympathetic to patients, they too have little or no access to doctors and in passing messages up the chain of responsibilities they can get distorted and delayed. These worries are often not passed on to doctors in a way that will produce the required information. The 'named nurses' system of allocating specific nurses to patients

throughout a stay in hospital depends greatly on the ability of the nurse and can be frustrating for patients since to some degree it blocks access to someone who may be more sympathetic; but most of all in the several stays in three different hospitals I have experienced recently this system is very unpopular with nurses, who simply don't operate it. Although much has been done to make hospitals more friendly places, including breaking down what seemed fearsome hierarchies of anonymous staff, according to all the patients I have spoken to, it doesn't help if they are left not knowing where they are. Not wearing uniforms and white coats and nurses being apparently more on one level and known by their Christian names, not having matron and so on does not help if they don't know where they are in relation to staff. They need to know who to speak to if they want a real difference and who is accountable for their daily welfare. They need to know that even more when they are really ill because they have no choice but to put themselves in the hands of a system which they feel will be watching out for them and have its own checks and balances. They need to know who can begin to make decision making, at least in part, accessible to them in a real sense.

It is most important for patient's wellbeing to feel that they have ownership and some control over their illness and that they can do things or behave in ways which will help themselves. The degree to which this is possible may relate to their recovery.

R: Right, there is

V: Is it a bit muddled?

R: No, no, not at all. I was thinking that there appeared to me to be quite an overlap.

V: Yes.

(Appendix 3. Valerie)

At the time this seemed straightforward. In a conversation I had with Valerie at a later date, she mentioned to me that whilst it was pleasant of me to discuss what I was trying to do in a collaborative way, she would have preferred if I had just told her what I trying to do. "I really wanted to know what you wanted out of it....I expected to be asked/ directed." In this way it would have been easier for her to fulfil my requirements and

hers!! (extract from letter from Valerie to me on reading the transcript). Clearly such an invitation for permission to research my practice is impractical at the beginning of every straightforward clinical consultation. In this case then, to some extent, deception is taking place. This constitutes the second ethical stance in research according to Denzin and Lincoln.

The deception model "endorses voyeurism in the name of science, truth and understanding." (ibid) This position is regarded as justified on the basis that a social scientist has a duty to contribute "to society's self-understanding." Any method that contributes to this is justified. Such a model attempts to justify itself on the basis that "people in power, like those out of power, will attempt to hide the truth from the researcher." (ibid) Such a model assumes that the researcher is in a better position to determine what is in the interests of society and assumes that the loss of freedom to the individual, who is the subject of the research, is counterbalanced by the increased understanding such research would provide.

In the third ethical position, the so called relativist stance, the researcher will "study only those problems that directly flow from their own experiences." Such an ethical position is more circumscribed than the absolutist and deception models because "agenda setting is by personal biography, not by some larger scientific community." Such a position relies upon the researcher's own set of standards to determine the ethical position of, for example, the degree of participation. The approach aims to "build open, sharing relationships with those investigated." (ibid) This position acknowledges that the issue of what is right and what is wrong in the research is determined by the researcher and justifies this by claiming that just as the research is researcher orientated, then so is the ethical foundation. Much of my research into my own practice adopts a relativist stance since much interpretation is self-referencing but as I will argue shortly, such a position leaves unconsidered the question of what is right and what is wrong.

The final two ethical positions have much in common. The contextualized-consequentialist model is "built on mutual respect, non coercion and non-manipulation,

the support of democratic values and institutions, and the belief that every research act implies moral and ethical decisions that are contextual." The feminist model springs from the contextualized-consequentialist model but particularly emphasises the "collaborative, trusting, non oppressive relationships between researchers and those studied." (ibid)Both these positions attempt to adopt a shared ethical stance in which the moral and ethical consequences of any decision or action is reasonably transparent. The concern is that such mutuality may be more apparent than real. The world in which the clinical interaction takes place, and the language used in the discourse, is much more under the influence of the doctor. "Social groups are prevented from achieving a correct understanding of their situation because they have passively accepted an illusory account of reality that prevents them from recognising and pursuing their common interests and goals." (Carr & Kemmis 1983 p137)

This interpretation suggests that knowledge is shaped by human interests. In this respect knowledge is linked to power, and as such, requires an ethical stance. Habermas contends that different kinds of knowledge are developed "on the basis of interests that have developed out of the natural needs of the human species and have been shaped by historical and social conditions. Without the whole range of needs and desires incorporated in the human species, human beings would have no interest in acquiring knowledge and there would be no possibility of knowledge at all." He goes on to construct three knowledge-constitutive interests which he labels the 'technical', the 'practical' and the 'emancipatory'.

Interest	**Knowledge**	**Medium**	**Science**
Technical	Instrumental (causal explanation)	Work	Empirical-analytic or natural sciences.
Practical	Practical (understanding)	Language	Hermaneutic or 'interpretive' sciences.
Emancipatory	Emancipatory (reflection)	Power	Critical sciences

He argues that language is so "distorted by prevailing social, cultural, or political conditions" that 'practical' interests can only be adequately pursued when "alienating conditions have been recognised and eliminated." (Carr & Kemmis 1983 p132-134) As a doctor I need to be aware of the extent to which the biomedical language that I employ in the consultation may distort the real interests of those whom it purports to serve. The contextualized-consequentialist and feminist ethical model attempt to at least be aware of this distortion and recognises the ethical position of failing to do this adequately. One might argue that two doctors both of whom are familiar with medical discourse might be in equivalent positions of power, even if they meet as doctor and patient, but this position is difficult to reach when a doctor meets a patient with little understanding of the medical discourse. At this point in the argument, knowledge, power and ethical considerations meet and it is insufficient to simply adopt a single ethical stance. The ethical stance it seems to me is overtaken by a moral one in which the researcher becomes principally concerned with what is right and what is wrong.

The current scene is illuminated by four basic theories of what is right and what is wrong. These include the utilitarian, the Kantian, instuitionism or common-sensism and a virtue-ethicist approach. (Honderich 1995 p593-595) The utilitarian maintains that the right action must " be understood in terms of human good or well-being" and more generally the right action is that action which is conceived as leading to or more likely to lead to " the greatest balance of human pleasure or happiness over pain or unhappiness." (ibid) This position underpins the moral basis of the Lincoln and Denzin's deception model but is controversial because of the potentially uneven distribution of such pain and pleasure. Medical research may have to confront the possibility of pioneering some treatments with patients who may not only not directly benefit but may indeed find their position made worse by such research, even though society as a whole may 'benefit' in the long term. If my own research into practice complicates and disturbs the doctor patient relationship by unearthing unhappiness inappropriately, I may not be able to justify this by a claim that greater happiness to the whole may ensue.

The Kantian position argues that a moral position must be "understood independently of all empirical and sensuous motives. Moral rightness in behaviour is a matter of acting consistently and rationally." (ibid) My research position challenges the notion of acting consistently by arguing that such consistency is based upon a consistent set of assumptions that themselves need to be challenged. I am also arguing that a rational position in terms of analysis may present an incomplete picture of events because there are phenomena that form important contextual components of the problem that are beyond rationality. It would be ontologically incoherent to adopt an ethical position upon a rational stance when trying to undermine the fixed rational stance of conventional medical practice.

The third approach of intuitionism or common-sensism insists "that there can be no unifying account of our moral obligations; these, it claims, are irreducibly plural, and the only general moral principles it is willing to recognise are prima facie principles-it is wrong to harm another, it is wrong to break a promise." (ibid) Such a position also fails to address the same problem of how to resolve the sacrifice of one person in medical research in the interests of the greatest good. Intuitively one can argue that any death is morally objectionable but common sense suggests that there may occasionally be a strong case for such course of action, for example in the case of Siamese twins where separation may allow one twin to survive. Nevertheless, contemporary medicine is founded upon the Hippocratic notion of "first do no harm" and the intuitive common-sense approach to morality is the one that at least feels familiar as a basis for a research position.

The virtue ethicists position is also founded upon the schools of ancient philosophy. A virtue ethicist believes "that right and wrong cannot be captured by independently or basically valid moral principles but is a matter of situational sensitivity (Aristotle) or of the expression or maintenance of fundamentally good or admirable inner motives or states (Plato)." (ibid) This position is felt to contain insufficient general principles to sufficiently constrain what "the moral agent does *outside, in the world, to other people."*(ibid)

Given this apparently complex position, what sense can I make of all this? Bannister (Bannister et al 1994 p142-159) has suggested asking four principal questions.

1. What is the purpose of the research? Why am I engaged in doing it?
2. Which parties, bodies, practices are affected by the research?
3. What are the implications for these bodies in framing the research questions and undertake the research in the way I have chosen?
4. Whose interests are served by this approach?

The espoused purpose of the research arose out of a practical difficulty in applying positivist based medicine in context. Such a project could have been tackled without the need for a more formal approach via a thesis and so one further purpose of the research was to obtain a higher degree. As the research progressed, and as my perspective as a constructivist developed, my involvement in the research began to include another dimension, a more political dimension. This arose out of an understanding of the way in which the medical world exercised its control on knowledge, through its use of medical discourse and through the institutional control of its organisations including hospitals and regulatory bodies. Part of the purpose of the research has become a desire to widen the notion of what constitutes medical knowledge beyond what is widely seen in the medical fraternity as proper knowledge. In this respect I see myself as part of a much wider debate between those who advocate an 'evidence based' and those who advocate a 'context based' approach to the practice of medicine. This has implications for other parties and bodies in medicine. At one level, I sense that what I now advocate serves to undermine the position of the doctor as the sole arbiter of what constitutes knowledge, and what constitutes good practice. At the same time I belong to an organisation, a hospital, whose espoused aim is to serve the community at large and from this perspective my approach does not feel like one that undermines. I am at the same time aware that I am using my position as a doctor to challenge the position of doctors in a way that might be difficult for someone who is not medically qualified. Is this a position that betrays trust? I think not, as the espoused aim of medicine is to work towards the

common good and if my position is wrong, I believe the institutions of medicine are sufficiently robust to rebuff any challenge from within the organisation.

Clearly, within this research frame, my interests are likely to be served but am I serving the interests of patients, other doctors and the medical institution as a whole? Can I adopt an ethical position that pays attention to interests other than my own? I do not know but the temptation is to claim to adopt a defined ethical position such as the relativist stance of Lincoln and Denzin. However, this single perspective would fail to acknowledge the complex position that I find myself in as a doctor/ researcher into the clinical problem; researcher into my own practice and researcher into theory. As a researcher I notice how inadequately such a stance describes what is taking place in the clinic but also as a researcher I notice how difficult it is to offer an alternative. The only position I can adopt is to claim awareness as a researcher of the two different paradigmatic positions of positivist and constructivist. and the different ethical stances each of these positions demands. This, I see as reflected in an attitude of inviting inquiry into inquiry method during interviews. For example, in my interview with Patrick we discussed the process of interviewing. We were halfway through the interview and found ourselves discussing our expectations from the interview.

R: *I wanted, I wanted to ask you if this interview was what you expected?*
P: *Uhh I, I rather hoped it would be like this. Uhh I thought perhaps it would be uhh you ask the questions and me responding largely with yes's and no's and uhh I, I felt that I was not being able to get over to you all of those subtleties which umm which are built into the interchange that happily we've had so far. Umm because otherwise umm you have to remain on umm gener', generalities. Whereas the truth is actually detailed and uhh and the subtleties of uhh of uhh understanding and how could I possibly convince you uhh without going into those details such as the, the uhh uhh the antibiotic uhh situation that arose which was very meaningful to me and I, I was surprised, as I've said, that umm that it wasn't to you uhh but then I often found that with, with many points that I might raise in, in consultation with doctors that uhh where I thought I was saying something significant umm it proved not to be from the doctors point of view uhh but,*

uhh, uhh and of course I hold it as being important and that's the difference. Uhh I might be uhh I might be uhh swayed by a doctor picking up a point that I thought was quite important and would mean something to me as a result of this reaction to it umm but I would still hold the umm the views that I held about importance which my doctor might not have.

R: *Can I respond to that?*

And later on in the interview:

R: *I'm, I'm aware that I'm largely asking you questions*

P: *Yes.*

R: *and uhh umm and I've very much enjoying it, the answers in this sort of dilemma. Is there anything uhh you want to change that a bit, and ask me some questions?*

P: *(coughing) Well not at all Richard. I think the, the story is with me rather than with you umm and what uhh has been said has uhh prompted from me uhh the sort of umm criticism if you like that I would uhh I would wish to umm level uhh in these exceptional circumstances.*

R: *Right.*

P: *Uhh these things would never be said to you under normal circumstances. It is because we are sitting down being honest with each other and you are asking me to tell you my true feeling, my honest feelings about uhh my uhh recent history and because I think I have something interesting to say to you and my motivation that I think is that perhaps there is something to be, to be learnt from it. Uhh I, I worry particularly about the many people who may be walking around today who, who have had radiotherapy for example*

(Patrick, Appendix 2)

At this point in the methodology section, the paradigmatic positions to enter as a researcher have been considered, together with what constitutes data in the realm of research interest. Thought has been given to what are my specific and general research questions and various methodologies have been examined to see how they may generate

data to develop understandings. Finally, the question of ethics and morality in research have been considered. The final section of the four main sections;

1. Ontological and epistemological issues in relation to a research question
2. Linking research questions, epistemology and methods
3. Ethics, morality and politics of the research process
4. Producing a practical research design

needs to consider how I put all this together to produce a practical research design.

Section 4

Producing a practical research design

I encountered three stages in developing a practical research design; co-operative inquiry, supported action inquiry and action science/ inquiry. At the onset of the research, in 1990, I set up what I believed to be a co-operative inquiry group of doctors. I started this co-operative inquiry group with the aim of exploring the non-clinical processes surrounding decision making with a view to integrating medical, positivist, quantitative knowledge with qualitative understandings. At the end of the first year, I could not see sufficient progress in understanding the relationship between qualitative and quantitative phenomena and whilst continuing to be part of the 'co-operative inquiry' group of doctors, gradually turned my attention to an exploration of the problem focussed more on my activity in the clinic. In doing this, I was aware that my participation in both the hospital inquiry group and the Postgraduate research group at Bath University (part of my supervision process and discussed in more detail shortly) was continuing to be valuable in what I thought/ felt/ experimented/ experienced in the clinic. As a consequence my practical research design was reconfigured in terms of Heron's 'supported action inquiry' model. (Heron 1996) In 1992, the hospital inquiry group disbanded but I continued to research my practice in the clinic but using action science/ inquiry as described by Argyris, Schon and Torbert. This progression of research design from co-operative inquiry, to supported action inquiry to action science/ inquiry can be seen to develop through this section.

The resubmission process has also encouraged me to reconstruct this final stage into a three level conceptual picture of positivist, reflective practitioner and researcher in a way the re-addresses my original puzzle of integrating positivist medicine with non-clinical processes. In other words, I have developed a model that allows me the flexibility to tailor treatment and paying attention to the process of doing this in a way that is not exclusive to quantitative or qualitative perspectives.

At the beginning, in 1990, I could see that it would be possible to research my practice in my own clinic using ethnography or action science together with supervision and participation in the Postgraduate research group at Bath University. I also saw the more exciting possibility of creating a co-operative inquiry group of departmental colleagues centred around the head and neck oncology clinic. This model would comprise a series of action (head and neck clinic) and reflection (hospital inquiry group) phases that seemed to conform to a co-operative inquiry methodology. I now propose to set the scene in more detail by explaining what took place in my own clinic and in the head and neck oncology clinic to show how they related to the hospital inquiry group as a co-operative inquiry methodology.

My personal clinical practice

Each week I would hold six three to four hour clinics. In each of these I would see anything from twelve to twenty patients. The problems would range from the apparently straightforward one of needing a hearing aid to complex and difficult decisions to be made by patients with unpleasant malignant disease. Most of the time I would be in the clinic alone with the patient but on other occasions medical students, trainee doctors, other colleagues or nurses would be present along with any number of relatives or friends of the patient. There would be one or two nurses in attendance.

The head and neck oncology clinic

This was specifically developed to plan treatments for patients with cancer of any part of the head and neck. I ceased to be a member of this clinic in 1993 as a result of a departmental reorganisation, so I include here a description of these clinics I made in 1991 and quote from my research diary.

"These clinics are held once a month on the second Wednesday afternoon starting at 2.00pm. Beforehand, for about an hour and a half, we meet over lunch held in the department. The lunch is principally a social event involving not only the medical staff

but also the nursing, audiology and secretarial staff. We usually listen to a short ten-minute talk from a pharmaceutical representative in exchange for lunch supplied by them. The rest of the time is spent in free conversation, general chit-chat, gossip etc. Occasionally a topic of general interest will emerge but much more often small groups talk amongst themselves. We are joined by the radiotherapist and oral surgeon at about 2.00pm and the clinic begins.

I can see that after an hour and a half of socialising there is quite a 'party' atmosphere. In fact these lunches were introduced in 1983 to try and instil a sense of cohesion, esprit de corp within the department. In addition, this 'party' atmosphere has enabled us all to gel into a group which perhaps increases the sense of 'being outside it all' that I suspect the patients experience when we saw them in the clinic later on that afternoon. The feeling I suspect is like arriving late to a party.

The clinic is held in a very relaxed atmosphere, at least I thought it was relaxed until I later learnt from the co-operative inquiry meetings that this was not the case. Everybody is standing, except the patient and possibly a relative, who are both given seats. Usually only one relative will be present because of a lack of space in the room. The medical staff are in small groups paying minimal attention to the patient unless they are directly involved as part of the decision making process. The conversation in these small groups can be medical, hospital politics, hospital gossip or frankly social but they are all held in 'sotto voce'. From time to time key members will come over to the patient to give an opinion and others are invited to observe, examine the patient etc. as part of the decision making or educational function of the clinic. This 'choreography' was believed to take some of the pressure off patients as they entered the room so that the process became more comfortable for them.

Every patient seen during the clinic has a head and neck malignancy and for most of them the problem is less than straightforward. Many of them are contemplating their own mortality or at the very least the end of life as they know it. They have cancers of the tongue, throat, voice box, sinuses, salivary glands or facial skin. It is obvious to all

concerned that the problem is serious and it is impossible in such cases to disguise this fact unlike a problem safely tucked away in the bladder or abdomen.
Before they enter the room, a medical history, a historical medical explanation of the problem, is read out by a member of staff to all the other doctors. One of us then goes to collect the patient from a crowded waiting room nearby. Usually other patients are waiting their turn, and often the consequences of treatment or disease are plainly there for all to see. It sometimes looks a little like a battlefield casualty room. No such 'party atmosphere' exists here. Perhaps if the patients and their relatives had met beforehand, over lunch like we had, they would have been able to generate a collective will, a collective determination that the individual could draw upon and demonstrate a collective sense of purpose in the same way as the medical staff.

Upon entering the room, the patient is introduced to key members of the medical staff. We used to introduce them to everybody but by common consent this was felt to be not only unnecessary but also agonising for all concerned. We take turns to examine. At the end of about five minutes the consultant in charge will say something like this:

"we find it difficult to talk honestly and straightforwardly about your problem when you are in the room. I wonder if you wouldn't mind stepping outside for a few minutes and then we will come and give you our opinion"

Together we discuss the problem. There is usually a difference of opinion as to what is the best thing to recommend. This difference may be due to many factors but seems to be dependant upon where your principal training in head and neck surgery has taken place. Some units have a reputation for being more surgically aggressive and this is reflected in the graduate. There is often quite a lot of laughter, but it doesn't feel like disrespectful laughter to us, but if it could be heard outside it might not have seemed so. I am often reminded of GK Chesterton's remark;

"We often laugh at what would otherwise be tragic".

We usually manage to come to a collective decision, which often includes an option or two which can be put to the patient. For example a common option is:

"we believe that your chances of survival will be reduced if we treat your cancer of the voicebox with radiotherapy, and you will be able to speak in a normal manner if it is successful. On the other hand, if we remove the cancer with surgery your chance of survival is improved but you will not be able to speak in a normal way. Do you have any feelings or thoughts on this particular point?"

The surgeon, radiotherapist and usually one junior doctor in training will then talk to the patient and relative(s) in a separate room, the room in which lunch was held. Meanwhile the next patient's history is being presented to the rest of the group. About ten to twelve patients are seen in an afternoon and the clinic finishes at about 5.00 to 5.30 with tea. Everyone is usually pretty exhausted. At the end nobody seems to enjoy the clinic much.

The conduct of the clinic contained much ceremony, which we all instinctively understand and may be supportive to our purpose, whatever exactly that might be. These include meeting beforehand to develop a sense of collective medical cohesion, the separation of the patients from the main body of the clinic in another room, the presentation of a medical history without the patient, the invitation to the patient to leave before any decision is discussed, the final discussion in a separate room all of which are part of a ceremony. Every doctor was aware of the sequence and control that such ceremony gave to the flow of information to the patient. The ceremonial aspects made it difficult to challenge the process and would unwittingly discourage any 'troublesome' questions. At the same time the ceremonial nature of it gave the clinic considerable authority and on many occasions patients expressed pleasure in seeing so many doctors coming together as a team to tackle their problem." (Research diary RJC)

The head and neck clinic met on a monthly basis and the possibility became evident that this decision making arena might be a suitable place to investigate decision making. I

therefore suggested setting up an inquiry group of the clinic participants with the general aim of examining decision making. This became known as the 'hospital inquiry group'.

The hospital 'co-operative' inquiry group.

This group was formed as an espoused co-operative inquiry group in the early phases of the research project and met on a regular basis for two years. In setting up this group, I was aware of two needs that would be important. First of all, there was the need to set up a structure that permitted action/reflection cycles characteristic of co-operative inquiry. Secondly, there was the need to have a topic, a research question that would prove to be sufficiently attractive for a group of busy doctors to wish to attend such an inquiry group. With this in mind, it seemed to me that there were a number of practical points to consider. At the time I saw the following as important.

a. I would need to form a group with a common interest in the research question.
b. The topic itself should have some authority in the medical world. For example, a suggestion to research the organisational relationship between doctors and managers probably wouldn't attract more than a passing interest from most of my colleagues.
c. Those participants in the group should find the topic relevant within their working lives even if they were to move out of hospital life into general practice.
d. It had to be a topic that made it practical to generate data during my clinical activities. It should mean that several times a day we would research the topic or at least think about what we were trying to do.

The group was composed of my consultant colleagues, the senior and junior registrars both of whom were career ear, nose and throat surgeons and the senior house officers all of whom were pursuing careers in general practice. This group met once a month, alternating with the head and neck oncology clinic, to discuss clinical decision making.

The co-operative inquiry model incorporated the head and neck oncology group and the hospital discussion group to form the action and reflection phases of a co-operative inquiry cycle. (Reason. 1988.p4-5)

Stage 1. ***The discussion group.*** A group of co-researchers would meet for about one hour to inquire about decision making in the head and neck malignancy clinic. At the end of this meeting, during which various problems within the clinic were discussed and the decision making processes were evaluated, we would agree to change some aspect of the clinic, some feature of the clinic. Thus we would hope to both improve the way the clinic was conducted and at the same time shed light on the way decisions were reached.

Stage 2. We would take the change or changes we had made to the clinic and agree to assess the impact on ourselves and others. Self observe, observe others and record these observations.

Stage 3. ***The head and neck clinic.*** We would experience these changes within the clinic and try to become "fully immersed" in our practice. We would note the effect of the change or changes we had agreed to make on the running of the clinic, paying attention to the patient, other colleagues and ourselves.

Stage 4. We would return to the discussion group and reflect on this experience and try to make some meaning of it. After this sense making stage we would return to Stage 1 and commence another cycle of inquiry.

Stage 1 and 4 would essentially take place in the discussion group and Stage 3 would take place during the head and neck malignancy clinic. Stage 2 would partly take place during the discussion group and to some extent during the clinic. The first few minutes of each clinic were spent reminding each other what changes we had agreed to make and obtaining agreement from those who were unable to or did not have the time to or did not wish to attend the discussion group. These cycles of inquiry would each take a month to complete.

Heron has identified two different approaches to setting up inquiry groups and proposes the terms Apollonian and Dionysian to describe the two approaches.

"I use the terms to refer to two different and complimentary co-operative inquiry cultures. The Apollonian inquiry takes a more rational, linear, systematic, controlling and explicit approach to the process of cycling between reflection and action.....The Dionysian inquiry takes a more imaginal, expressive, spiralling, diffuse, impromptu and tacit approach to the interplay between making sense and action."
(Heron. 1996. p45)

My approach was to set up a co-operative inquiry group in a way that sought immediate engagement with the methodology as an exploratory device for two reasons. Firstly, as a way to develop a more reflexive approach to qualitative research by setting up a group that encouraged its members to challenge assumptions and interpretations by inviting appropriate feedback. The hospital discussion group seemed to offer a better opportunity than other occasions in hospital life to do this. In this respect it seemed to work well. For example, one meeting discussed the significance of calling one another by Christian names at work. Although we were inexperienced as qualitative researchers, I had never experienced a similar occasion in hospital when such a discussion involving consultants, trainees and medical students had taken place. It was also an exploratory device in the sense that actually trying a methodology was going to tell me more about co-operative inquiry than reading about it.
As a researcher, I notice how impulsive, how Dionysian according Heron's description, such an approach appeared to be and how much of a contrast such an approach is to the rather controlled, rational and analytic behaviour of the positivist paradigm. There may have been a number of reasons for doing this. It may have been partly a deliberate rejection of the more rational, explicit, controlling analytic approach to research that had been my experience to date. The experience of being able to playfully offer interpretation was a distinct contrast to what I had been used to. Finally, instinctively it 'felt' appropriate and the very term 'action research' seemed to encourage the idea of having a

go. The fact that I chose to follow a research strategy based on instinct ("it felt right") already says something about a shift in paradigm.

This temptation to act in this way appeared to have two safeguards. Firstly, I was confident that I had an innate, albeit imperfect, understanding of what was happening in clinical practice and that this innate understanding would guard me against forming any conclusions that would seem spectacularly inappropriate. Secondly, participation in the postgraduate research group at the university provided a touchstone to what might happen in the hospital co-operative inquiry clinic.

The Postgraduate Research Group at Bath University

The Postgraduate research group was formed in September 1990. In the beginning there were eleven research students and two supervisors, Dr Peter Reason and Professor Judi Marshall. Two students left after the first year. The remaining nine students came from various walks of life. They comprised a psychologist, an art therapist, senior nurses, a nursing academic, an engineering lecturer, a senior policewoman, a business consultant, a management academic and myself, a surgeon.

For five years, we met for one day a month during the academic terms. For the first year we talked as a single group but thereafter we usually spent the day as two smaller sub-groups. My group comprised a hospital clinical psychologist, a hospital art therapist, a senior nurse, an engineering lecturer and myself. Dr Peter Reason was our usual supervisor. As I took part in the conversation I would take notes. When I look at the topics we discussed in the early years they include such items as the nature of knowledge, particularly what was meant by knowing, gender, power, learning, territory, process, critical subjectivity. In the later years, words such as 'elegance as a validity concept', connected knowledge, 'growing edge' in thinking are hinted at throughout my notes. There would always be a session when we would review our own projects and about an hour was given to such a review. On four occasions I brought along a video of an

outpatient consultation and the group watched this, made suggestions, comments, observations and critical analysis.

How did I work with and within the postgraduate group? The day would start with general introductions and then a search would be made for a theme to develop and explore for the day. We might select for example a theme based on 'experiential knowledge and what it means for each of us.' This would be a core topic around which the discussion and critical comment would revolve. At the end of the day we would attempt, not always possible, to summarise the key issues raised. From the early stages I learnt to adopt a duel role in these discussions. At one level I would be participating, contributing and carefully listening to what was being said. At the same time I would be constantly asking myself the question, "*How does this relate to my own research project*?" If I saw a relationship, or if this internal conversation generated an idea, a new approach, a question to ask myself, the hospital group or patients in the clinic, I would make a note of it. This group discussion, where alternative interpretations were discussed, where my inferences could be challenged, where the discrepancy between my espoused theory and theory in use could be brought to my attention was the principal means of developing two changes. Firstly, it resulted in a shift from positivism towards constructivism as I began to unpick the assumptions I had overlooked as a positivist. Secondly, these discussions, I believe, helped to develop a critical subjectivity.

During the first year it became clear that the relationship between the two main groups was complex. I began to notice the way I would participate in each of the two groups and the way they would relate to one another. The simple model I started to develop as a researcher can be depicted thus;

Postgraduate Research Group Full Learning of qualitative methodology
Partial Research into decision making

Hospital Research Group Full Practice of qualitative methodology
Full Research into clinical decision making

This relationship seemed to make it possible to try out reflexive approaches gained as a member of the postgraduate group within the hospital group and in time both these groups became forums for the development of facilitation skills, processing awareness, identification of themes in discussions and so forth. By the end of 1991, I began to see my activity in the clinic as part of a third "group", the doctor/patient group and so this group became incorporated into the set of relationships.

Postgraduate Research Group Full Learning of qualitative methodologies
Partial Research into decision making

Hospital Research Group Full Practice of qualitative methodologies
Partial Research into clinical decision making

Doctor/ Patient Research Group Full practice of qualitative methodologies
Full research into clinical decision making

Although at the time I perceived the relationships as developing the methodology of co-operative inquiry, in retrospect I see the process as one that contributed to the development of reflexivity by encouraging a relationship between reflection and practice and back again. However, this relationship between reflection and practice was enriched by transition through each of these different groups with the postgraduate research group.

Heron called this research relationship 'supported action inquiry' in which person A educates person B in the use of action inquiry and:

"Once B has got the hang of it, B is the primary researcher of his or own behaviour and A is only partial co-researcher. A has a secondary, supportive role, participating with B in regular reflection phases, discussing and facilitating ways in which B can make sense of past action and prepare for future ones, and make more congruent the interaction of B's goals, strategies, actions, outcomes and context."
(Heron J, 1996. p24)

Supported Action Inquiry

Heron sees this form of 'supported action inquiry' as having boundaries that are semi permeable between sets of relationships and which may offer different levels of participation for different actors. Using his approach I have constructed the relationships in a way that I saw as applicable to my situation in the following way:

Postgraduate Group

(reflection.....practice)

Nature of boundary between groups	Self Group	?Open/partial ?Closed/partial
Participation in decision-making research	Self Group	Full Partial
Participation in experience:	Self	Full in postgraduate group Full in hospital group
	Group	Full in postgraduate group Nil in hospital group

(practice.....reflection)

Hospital Group

It was also possible to construct a similar picture to describe the nature of the boundary and participation that existed between the clinic and the postgraduate group. Because the

postgraduate group were able to view some videos of my clinical consultations, I see that this enables them to view 'data' directly and increase their involvement in the decision making research.

Postgraduate Group

(reflection.....practice)

Nature of boundary :	Self	Open
	Group	Closed/partial/open
Participation in decisions:	Self	Full
making research	Group	Partial (video)
Participation in experience:	Self	Full in clinic
		Full in group
	Group	Nil in clinic
		Full in group

(practice.....reflection)

Patient/ doctor

At one level, I am suspicious of the neatness suggested by such a model, but it did serve to encourage a separation of action and inquiry, together with a slowing down of any interpretations that might be suggested. This was seen particularly in the way that consultation videos were made in the clinic to be discussed in the postgraduate research group.

Action Science/ Inquiry

After a while (1990-1992) this attempt to set up a co-operative inquiry and then supported action inquiry ceased to be sustainable and the reasons for this will be discussed in the next section Reflections on Clinical Practice. From this point onwards my research methodology was centred on action science (after Argyris and Schon) and action inquiry (after Torbert). Research into my practice was supported in two ways. Firstly in my continued participation in the postgraduate research group at the University

of Bath and in the use of more extensive interviews with patients, which I will now describe. On three occasions I undertook more detailed interviews with patients. The complete transcripts are presented in Appendices 1,2 &3. They are the stories of David, Patrick and Valerie. David and Patrick were both patients in whose care I had been involved. The interviews lasted forty minutes, one hundred and twenty minutes and ninety minutes respectively. Their clinical problems, the circumstances surrounding how I came to interview them and the process of recording, transcribing and correcting that took place will be described in more detail in the next section 'Reflections in Clinical Practice'.

How do these three methodological approaches relate to one another?

This evolution as a qualitative researcher, which might justifiably be seen as jumping capriciously from ethnography, to co-operative inquiry to supported action inquiry to action science, has resulted in a complex story but it is one that makes sense to me in two ways. Firstly, it charts my development as a qualitative researcher and secondly it documents what I saw as the impracticality of sustaining the hospital inquiry group. My sense making of my development as a qualitative researcher has been possible by examining the whole process in terms of shifting paradigms in the forms of the model described earlier on in this section.

Level 1. In my role as a doctor I operate at one level as a positivist (positivist theory behind data production).

Level 2. At the same time I work as a reflective practitioner/ action inquirer (theory underlying nature of data and data production)

Level 3. As a researcher (theory behind theory production) I try to develop an awareness of the ontological position I am adopting.

This means that the whole process is now seen as an attempt to develop a critical reflexivity developed around a need to work in more than one paradigm made necessary by paying attention to both evidence based medicine and qualitative issues.

How was this grounded in data?

As my ontological position was shifting towards critical theory and constructivism, then I needed to consider sources of data that helped me to decide whether findings are value mediated and/or created as the investigation proceeds. At the same time there was a need to develop an understanding of how I, as an investigator, influenced these values. In particular, I needed sources of data that allow me to see;

a) my perspective as a doctor more clearly
b) the perspective others, especially the patient, with more authenticity

At the onset of the research, my existing theory of medicine in context was either incomplete or inappropriate. Others have advocated that when "prior theories concerning contextual aspects of an expert's knowledge in any particular domain are absent, then under such circumstances the inquiry tends to take a more generative approach." (Henwood & Pidgeon 1993 p20) This suggests that data generation needs to be firmly grounded in everyday practice. There are practical as well as theoretical reasons for this approach. It would not only be practical to think about data generation and theory generation during the clinic but such data and theory building would take place in context. Since the original motive for research is the problem of applying positivist theory in everyday context, such an approach would represent at the very least an ontologically coherent approach. It would also permit, when appropriate, an opportunity for exploration of the value laden nature of data. For example, if I ask the question, 'do I have an ethical position about participation in decision making?', it is then possible to explore the question in context, with the patient. All this suggests a grounded theory frame to data generation.

During the research, I became aware that I made many claims that could not be substantiated or which could only be weakly substantiated. For example, I was unable to say that I have raised my level of inquiry only that I *believe* that I have raised my level of inquiry. The basis for this is that I notice internally that I am asking more questions and this claim, even when made on a *critical* self-referential basis, represents at best only a weak form of justification. This can be viewed from two stances, that of a practitioner and that of a researcher. As a reflective practitioner, I notice that the world becomes more problematic because I have developed more of a self monitoring look that adds to the complexity of what it means to be a self reflecting practitioner. The importance of context, the theory and value driven nature of data, and an awareness of the assumptions of positivism mean a radical shift from the more straightforward position I had adopted as a conventional doctor. As a practitioner I have noticed that working like this appears to be more satisfactory but as a researcher I notice that it is difficult and contentious to demonstrate to others (which is of course data). As a practitioner, I notice how much more satisfactory my practice has become, but as a researcher I also notice how difficult it is to prove to other people that this is also the case (which is also data). This is largely because so much of the data is in my own behaviour in levels of comfort, surprise etc (which is also data). All this suggests the need for a critical self-referential frame to data generation as well.

Reconstructing the methodology as part of the resubmission has allowed me to formulate more clearly how, in my current practice, theory is developed from data framed in three different ways;

Positivist frame
Grounded theory frame
Self referential frame

This threefold approach has acted and acts now as a guide in trying to develop a capacity to understand in the following ways. The positivist frame allows me to develop the positivist basis of contemporary medicine. The grounded theory frame acts to remind me

that data is theory and value driven and circumscribed by assumptions, which allows non positivist data a 'voice'. The self referential frame allows me to make conjectures with reference to my own position and asks questions as a researcher with a view to becoming *critically* self-referential.

The methodologies employed to generate data in the positivist frame do not directly form part of this research and I do not propose to discuss them in detail other than to raise two points. Firstly, to acknowledge the incomplete picture obtained when considering a medical problem solely from within the positivist frame and this has been alluded to in previous sections. Secondly, to recognise that there are ethical concerns about the nature of positivist research when viewed from the qualitative perspective and these have already been discussed.

The methodology employed to generate data and theory in professional practice is employed in the clinic, during the consultation process. Such a methodology needs to be 'in the moment' so that assertions can be challenged, questioned and reformulated as part of the decision making process. Inquiry can be raised to allow assumptions to surface about non-clinical processes such as power and gender which may be germane to the consultation. Action science is a methodology that claims to be epistemologically and methodologically coherent with doing this. Given the very short nature of some consultations, it would also appear to be practical but that in itself raises an issue. Does this process simply become nothing more than ethnography? Is the consultation too short, given that one is also trying to complete a medical task, to allow different viewpoints to emerge and different assumptions to be properly tested. Action science looks at the incongruity between the theory espoused and the theory in use and such a short consultation time might not be sufficient to test this incongruity sufficiently rigorously, certainly in the individual case.The difficulty in presenting a credible case that real inquiry took place is highlighted in presenting this work as a PhD thesis.

Credibility in clinical practice

I have attempted to address the problem of credibility by trying to throw open my practice for others to see. The aim is to challenge my own sense making with alternative views from outside. I have tried to do this in four different ways. First of all by the use of more detailed interviews and the interview data (Appendix 1,2 &3) are given as examples of what I was doing. Although such interviews do provide more time and space to explore issues, they are not simply extensions of the consultation interview lasting one and a half hours rather than five or ten minutes. They are interviews about the nature of my engagement as a doctor rather than the original data of the consultation. I was asking for data on how I could have done this differently; what were the problems generated by my approach? Such an inquiry could be done in a way that was not possible in a busy clinic, that needed a little time and space to emerge. The following example is taken from an interview with David. He had been a patient of mine and I was asking him for some feedback on how he saw our relationship and the way the medical problem was managed. The numbers in brackets represent pauses (in seconds) in speech.

R: *Mmm.* ***(2).*** *I'd very much welcome some feedback about the part I played. I mean*

D: *Mmm.*

R: ***(2)*** *umm* ***(1)*** *How did you view our relationship and the discussions we had? What was, what was the good thing, was was the bad thing, what, what, what*

D: *Well there, there, there was, there wasn't a bad side to it Richard, I was absolutely <u>delighted</u> that you were frank with me. Uhhh. I think you, you, you were very kind in the way that you put it. You, you didn't pull any punches but it wasn't brutal whereas the bloke at the, the Marsden Clinic, I mean that was a* ***(1)*** *disgusting carry on. Uhhh*

R: *Mmm*

D: *No, I, I, huhh, in all things I like honesty and in coming to see you, I asked you what the prognosis was and you told me. You told me probably the*

kindest possible way that you could without pulling any punches and I was very, very grateful for that. Umm. Had you not told me in that way and had I not found out for a fair length of time, I think I'd have been a bit annoyed actually.

R: *Right.*

D: *Because at least it gives you a chance to well* ***(3)*** *I don't know, put, put yourself in order, start to fight it, start to make your decisions but in, in my view it was exactly the right way to treat it and the right thing to do.*

R: *Right. And I, I don't mind you, I really don't mind you being critical in any way because I'm interested to learn but would there be anything that you would have done differently or uhh is there anything that I failed to understand.*

D: *No. No, not at all. I think* ***(3)*** *there was just one, one, one element when I, I started to tell you about going down to see this bloke George in Wales*

R: *Yes, I know, I remember that.*

D: *"Don't Dave, don't tell me". (Laughter.)*

R: *Did I?*

D: *Yeah, yeah. (Laughter). And I thought well, come on Richard that's a bit closed minded. (Laughter).*

R: *Thank you. I think the trouble is, umm, I, I, I, I will try to be more open about these things. It's very difficult. What, what ends up umm is people start asking advise about whether or not they think*

D: *Yeah.*

R: *they should go but the trouble is, I have no experience at all.*

D: *No.*

(Appendix 1. David p12-14)

The reservations David had about my 'open mindedness' took some probing and some time to emerge. In a busy clinic it is hard to imagine there would be the time to genuinely explore such issues. As such it also permitted exploration of many other issues. Where had I made assumptions? How did he react to certain information I gave him? Were my

assumptions about what was happening justified? They are interviews about the consultation process and represent an inquiry in their own right but they also pay attention to the purpose of the consultation, that is trying to make someone better. I am also trying to make an assessment of the relative usefulness of such interviews at the time. As I hope to demonstrate in the following section, these interviews not only allowed me to explore my own espoused theories but challenged them. For example in the interview with Valerie, reaction to my position as a white middle class professional male doctor (discussed later in the section on power) and the assumptions that go with such a position, was a perspective that I had never been given. This may have been largely because in my position as a doctor, I am surrounded largely by white middle class male doctors. I believe that such interviews allowed me to examine this position more carefully. The interviews also highlighted and challenged a number of issues; agenda setting in interviews, the role of alternative medicine, space and noise in hospitals as expressions of power, the role of family and friends in decision making and many others.

Secondly, I have taken videos of my clinics to the postgraduate research group at the University of Bath and we have viewed them together. These were examples of everyday 'straightforward' consultations. This was undertaken on four occasions and on each of these occasions the videos were seen and discussed by the group for a period of approximately two hours. This process generated insights that were in time translated into changes in practice. I gave an earlier example of how one member of the group (PR) noticed that I would lean forward and examine someone's ear, adult or child, without asking permission. This gave rise to a discussion about the nature and importance of touch, implicit permissions and the assumptions that go with these, which eventually led to a change in practice and a topic for discussion when teaching clinical examination. Other examples of the way that observation from watching videos of consultation changed practice include; observations that during the consultation many people were coming and going in and out of the room; the way I would interrupt answers; questions were formulated by me in such a way that made short answers more likely; and that I am fairly large as an individual and often hunch myself up.

The third means of opening my practice to others was when I was accompanied by a colleague, trainee, medical student or nurse in the clinic. I would formally ask them to comment upon my consultation process. What did they notice about my consultation style? This invitation included a specific request to suggest changes that might help to improve it.

The final means of throwing my practice open to others was in the hospital discussion group. This group was initiated to explore questions of consultation style and decision making and provided another opportunity to examine the incongruity between espoused theory and theory in use.

Opening my practice in these ways was an attempt to get beyond a series of small anecdotes. It represented an attempt to reach a level of engagement where I was trying to notice my own behaviour at a micro-level on a systematic and regular basis and if such inquiries are to be regarded as self-referential, they represented an attempt to do so at a critical level. One could also argue that this criticism itself represents nothing more than an attempt to impose the idea that there is generalised 'objective' knowledge based on the positivist ideal of systematic, comparative, replicative observation that is "used as a point of reference against which *all* research is judged." Some have argued that "such an approach to evaluation is based on a major fallacy and logical error in that rules for conducting research are mistakenly seen as rules of justification to be used in the evaluation of knowledge." (Morgan 1983 p396) It seems to me that Morgan is proposing an argument here for accepting the status of validity criteria that are essentially 'self referenced', but that the researcher would still need to look for internal validity criteria that satisfy him or her of the quality of what they have described. It seems mandatory to generate validity criteria that satisfy my own concerns about truth and which seem, at the same time, credible to others.

Validity

Validity is concerned with the criteria for judging the quality of an inquiry and is once again dependent upon the paradigmatic position of the researcher. The validity criteria of positivism and post-positivism are based around clarity and stability of findings. This means that research quality is based upon "isomorphism of findings with reality" to support internal validity and "generalizability, reliability (in the sense of stability) and objectivity (distanced and neutral observer)" (Guba & Lincoln 1994 p114) to support external validity. The critical theorist assesses quality by the extent to which the "inquiry acts to erode ignorance and misapprehensions, and the extent to which it provides a stimulus to action, that is to the transformation of the existing structure." (ibid) This position takes into account the historical and cultural context of the inquiry. Two sets of validity criteria have been proposed for constructivism; trustworthiness and authenticity.(ibid) The trustworthiness criteria are "credibility (paralleling internal validity), transferability (paralleling external validity), dependability (paralleling reliability), and confirmability (paralleling objectivity)". Authenticity criteria will include concepts of "fairness, ontological authenticity (enlarges personal constructions), educative authenticity (leads to improved understandings of the construction of others) and catalytic authenticity (stimulates action)." (ibid) However in the constructivist paradigm the parameters of quality are not universally agreed and alternative views have been expressed that do not stick closely to equivalents from positivist paradigms.

To a constructivist, validity "has to do with the adequacy of the researcher to understand and represent people's meanings" (Banister, Burman, et al. 1994 p143) and a number of criteria have been suggested to judge quality. These include the following. Keeping close to the data to produce a public product. Building theory that is rich, complex and dense, which pays attention to the complexity of the situation under study. Maintaining documentation on values and assumptions as the research progresses. Exploring cases that do not fit and maintaining sensitivity to alternative explanations offered by participants. Producing detailed descriptions of context to increase the possibility of similar studies arriving at similar conclusions and finally developing a reflexive approach

that "acknowledges the ways in which research activity *inevitably* shapes and constitutes the object of the inquiry." (Henwood & Pidgeon 1993 p24-27) Reflexivity "refers to the way in which all accounts of social settings-descriptions, analyses, criticisms etc-and the social setting occasioning them are mutually independent." (Cohen & Manion 1989 p33) This recognises that theory will affect the way data is generated and subsequently explanation. This problem is partly overcome by "an exploration of the ways in which the subjectivity of the researcher has structured the way it is defined in the first place" and in this way "subjectivity is a resource, not a problem." (Banister, Burman, et al. 1994 p13)

In the participatory paradigms, with its emphasis on the importance of practical expertise, the challenge to develop action/ practitioner validity criteria is clearly thrown down;

"For a skill, knowing how to do something, can never be reduced to written descriptions of doing it. Being able to write such a description is no evidence of being able to perform the skill. The only evidence that you have the skill, and have it up to a certain standard of competence, is your demonstration of it.....Thus the challenge to the academic research establishment of the primacy of the practical is that published research reports become entirely secondary to the researcher's demonstration of competence in action"
(Heron. 1996. p21)

The difficulty encountered in describing a skill is very important to me. Part of my frustration in writing a convincing account of a change in practice, is that I am aware that my skill as a writer may be used as the sole criteria by which my skill as a practitioner is judged.

Since my espoused position as a researcher is one of an awareness of paradigm, sometimes operating within the positivist framework and at other times adopting a constructivist position, then I have to ask how these different and conflicting criteria of validity relate to me. How have I shifted from positivism to constructivism with at the onset, only judgements of quality based upon the positivist perspective? What have been the problems associated with doing this? Is it an authentic position to take because a

constructivist might argue that at the level of belief this multi-paradigmatic perspective simply represents an attempt to impose order on research by sidelining much interpretation into a compartment labelled "constructivism". This is what some have described as an attempt to deal with the crisis in positivist research "by suppressing it" (Parker 1989)

As a researcher I am aware of a number of problems associated with this shift. The first one is the question of complexity. A hallmark of positivist research, and one criteria upon which quality is judged, is simplicity and clarity. As a researcher in the positivist paradigm, I am always looking to simplify situations, extract simple understandable and transferrable relationships from complex data. When these simple relationships suddenly emerge from complex data, for example when a treatment protocol clearly gives extended survival, there is a sense that a real discovery has been made. The simpler and more clear cut the relationship, the more transferrable such a finding would appear to be, so clarity is a meta criteria for validity. By contrast, complexity is a distinguishing feature of explanation in the qualitative field of complex phenomena and attempts are made to increase this complexity even to the point of chaos and confusion; "some confusion suggests deeper levels of meaning." (Banister, Burman, et al. 1994 p142-159) As a researcher from the positivist tradition, I have found it hard to overcome this tendency to avoid complexity and remain aware that I continually seek to impose order upon situations even to the point that I might overlook data that makes a situation complex.

At one level this approach makes the situation paradoxically even more complex. If I attempt to limit complexity by "tightening up the procedures so that the subject cannot possibly guess or interfere with the hypotheses", I am suppressing speech, suppressing data and suppressing meaning. Any understanding of what is happening now depends upon interpreting correctly the effect of this suppression. (Banister, Burman, et al. 1994 p6) By contrast, suppressing meaning makes it *appear* to be less complex. As a practitioner this latter approach is understandable when one considers the fact that clinics are complex enough as it is. The process of greatly increasing complexity by 'making data boundaries leaky' sets up a tension between " 'personal reactivity' (the attempt by the

'subject' to understand and control the research) and 'procedural reactivity' (the ways in which the demands of the situation limit their room for manoeuvre)." (Banister, Burman, et al. 1994 p15) This may be reflected in consultation style as a practitioner (suddenly shutting the door on data offered by the patient when the waiting room is bursting at the seams). At the same time it leads one to ask questions about the process of researching (what is the theory behind research?). Is this control of data reflected in research theory by continually imposing order on explanation by marginalising discomforting data. As a researcher do I continue to shy away from complexity as a measure of explanation? Do I still at heart adhere to the notion of independent variables and is this reflected in my model of framing (positivist, grounded theory and critical self-referential) and researcher model (as positivist, constructivist and researcher)? Such questions give me a sense of the depth to which I still instinctively adhere to explanation offered by one paradigm, even when I sense that I have already made a real intellectual shift. My wish to impose order is firmly rooted.

In contrast to this I have noticed that a shift to a more complex constructivist viewpoint has allowed all kinds of data previously overlooked to enter, especially data from patients. I have begun to accept qualitative information that is non-medical from the patient ("I have a sense that I have something more serious going on") and in my own mind accord it equal status with, for example, an important blood result. I have learnt to make this process explicit to the patient. What I have noticed, as a practitioner, is that this strategy appears to produce a more satisfactory consultation. I cannot easily prove this, just sense it. This leads me to ask myself, as a researcher, how have I internally validated such a change that 'appears' to work as a practitioner but whose basis for belief is at odds with my positivist criteria of quality. How have I addressed this incongruity between behaviour and, as it were, belief.

In order to do this, I found that I started to develop a series of qualitative criteria by which I could judge the quality of change. At the heart of all this is practice, professional practice, and in the early stages evaluating new knowledge was based on noticing change.

These are essentially based upon the notion of bringing past experience to bear on a situation. Earlier in the methodology section I suspended the argument on 'usefulness' and promised to return to it when discussing validating change in practice and do so here. It seems to me that validated change in consultation style pays attention to 'usefulness' determined not just by the doctor but by the patient as well. To do this, I conceived the notion of authenticity; personal, medical and political authentic behaviour, to internally validate this change and they included the following outlined below.

1. Did working in a more authentic way prompt patients to move towards a world where the balance of power felt more evenly distributed? Could others access my medical expertise and use it more effectively for themselves?

2. Did a change in consultation style allow patients more time to make a decision as the complexity of what was being decided was more clearly made? Was I showing them how to implement this?

3. Did analysis of apparently 'simple' problems take me much longer as I would unearth many issues hitherto left uncovered?

4. Did a change in practice make the consultation more anxiety making, more stressful, more disturbing or more rewarding for the patient and for me? But at the end of this did we both feel that the process was worth exploring, i.e. constructive?

5. Did working in a more authentic way make me feel in some situations more connected with what was happening to the patient? Did I feel more involved, more understanding of the difficulties in deciding, more upset sometimes by the interaction?

6. Were any ideas I had, any changes that I had introduced into my practice, sustainable? Was I still adopting the same general approach a year or so later? This is closely related to the notion of consistency as a qualitative validity concept. (Banister, Burman, et al. 1994 p143)

7. Did any ideas I had, any changes that I had introduced into my practice, lead to other ideas that were themselves sustainable?

8. What degree of "passion" did I feel about this?

9. Was the language employed consistent with an authentic process? Did my language change as I became more careful, more thorough in my approach, more aware of the relationship between power and language?

10. If I tested out some of these ideas on other doctors who also spent time in the clinic, did their comments and observations have meaning for me and them?

11. Did I find undertaking research in this way exciting and intellectually freedom making?

12. Did these changes generate an emotional response e.g. 'embarrassment' as I learnt how I had previously misinterpreted events?

In many respects, what I had previously judged to be early expressions of internal validity represent a new set of questions concerned with *process* that I had hitherto never asked myself. In this respect these criteria are evidence of raising the level of inquiry by raising the complexity of explanation but they still suffer from the criticism that they are self-referentially constructed and not accessible to others. Nevertheless, as a researcher I took the view that they provided evidence of an alternative means of validating findings to provide sufficient impetus to continue the shift towards a constructivist paradigm-an example, I would propose, of 'catalytic' authenticity.

The last criteria of 'embarrassment' was usually associated with discovering that an inference that I had made was incorrect. For example, understanding the importance of 'embarrassment' arose from an occasion when I had made an error of interpretation by

judging purpose solely on the basis of behaviour (strategy). The occasion was a qualitative research conference in 1994 during which I had met a participant again four years later. On the first occasion I had made the following judgement.

Hawkwood Sept 1990.
(unedited extracts of research diary in italics)

The smaller group met on the first afternoon and fairly quickly, as part of the introductions we made to one another, we all learnt what each one of us had as jobs, interests etc. One of our group, I shall call her Greta, a psychotherapist aged about 65, after learning that I was a surgeon made it clear that she regarded herself as the victim of a number of surgical errors of judgement over her lifetime. She recounted how she had been the victim of a series of inappropriate operations, which had been made worse by unexpected complications. I'd ended the day by feeling that she was expecting me to bear all the responsibility for errors committed by other surgeons towards her..... What I really wanted to say to her but didn't was: "If you weren't so fat, then maybe the surgeon would have had a chance. Besides you seem to be so opinionated I'm surprised that you were unable to take over and tell the surgeon just what you think should be done."

Four years later at another Qualitative Health Conference (Hawkwood 1994), I had spoken to Greta about our initial meeting and asked her what she thought had happened.

Research Diary, Hawkwood Sept 1994
"Found myself talking to Greta (sic) at supper this evening. It is four years since we first met in the small group run by Peter and the third conference we have attended together. I found my initial irritation of her had gone and that I liked her and found her easy to talk to. After we had been talking for about five minutes about the events of that day, I mentioned our first meeting. I explained my annoyance at apparently having to accept the burden of all the mistakes made by all the surgeons, with whom she had dealings. She first of all acknowledged that she had been aware of going too far in blaming me for her experience with doctors and apologised. I had been correct on this point. What

followed took me by surprise. She added that she liked me immediately and that I was the first surgeon that she had met who she had liked. For the first time she felt able to say what she really meant about the medical profession to the medical profession. ***How embarrassing.*** *My interpretation of antagonism had been founded on my own reactions and prejudices whereas she had seen the opportunity to be honest with someone, based on the opposite sensation of attraction.*

When we met on the second occasion in 1994, I learnt that my interpretation of what was happening between us in 1990 was incorrect. I had badly misunderstood the situation from her perspective and was embarrassed at being so completely wrong. This re-evaluation left me feeling *inwardly* embarrassed. The embarrassment I felt had in some way to be a reflection of the *shift* in position that I had made in the previous four years. Consider for a moment the processes I had gone through before reaching the feeling of embarrassment.

In order to avoid awkwardness in a situation in which I felt unfamiliar, I had avoided saying what I really wanted to and I had attempted to hide my true feelings. There was a discrepancy between my cognitive position, the way I presented it and what I was truly feeling. This situation gives rise to two potential sources of embarrassment. In the first place, if I had failed to disguise my true feelings and made clear from the start how I really felt about Greta, I would have broken a social convention about being so honest, so early on. "The discomfort of personal embarrassment can itself ensure that most people will do more or less the right (i.e. organisational) thing with clients, customers, colleagues and bosses."(Fineman. 1993. p17). That much is perhaps self-evident. There is a second source of embarrassment linked to loss of credibility. If I disguise what I was truly feeling from Greta and the other members of the group, but at a later stage my true feelings become apparent, such a change would leave the members of the group uncertain of my position from then onwards. My credibility would be compromised. If on the other hand, I managed to continue to maintain my true feelings covert and adopt a public position of civility, but at a later stage discover that I was incorrect, then such a shift would result in internalised, personal embarrassment. It seemed to me that the sensation

of embarrassment provided information about the quality of a shift in my position, my understanding of events. In this particular case, I discovered that I had made judgements about someone based largely on appearance and behaviour whilst completely failing to check out the validity of such a judgement. It was beginning to seem to me that embarrassment, when experienced in this way, could be regarded as a validity criteria in the sense that it is indicative of a shift in position.

Summary of Methodology

The methodology section has addressed issues of paradigm, what constitutes data and the methodologies to generate further data and understandings. These have been linked with my basic and general research questions to produce a set of practical research designs. The reconstruction made possible by resubmission has meant that I understood this in terms of a shift from 'co-operative inquiry' to 'supported action inquiry' to 'action/ science inquiry' of the reflective practitioner type. The process of integrating quantitative (positivist) data with qualitative data is understood in terms of a three level conceptual model of positivist, reflective practitioner and researcher. I have also considered the problem of producing an account of researching practice that is seen as credible and valid and suggested some of the criteria I have found useful. If the complexity of the methodology described above appears overly complex, uncertain, and capricious, I would argue that "the law of 'requisite variety' may be appropriate here; the complexity of the phenomenon is mirrored in its representation. Simpler formulations are entirely possible but they should alert one to the drawbacks that such formulations contain." (Clegg 1989 p215)

The next section is an account of what took place in the clinic and the hospital inquiry group. I try to produce evidence of how my understandings changed my practice by using data from events in my clinic, the hospital inquiry group and interviews with patients to produce a series of frameworks that I found useful in integrating quantitative and qualitative perspectives.

REFLECTIVE CLINICAL PRACTICE

Introduction

This section tells the story of my change in clinical practice from 1990 until 1998. In telling the story I draw on experiences from the hospital inquiry group, my day to day consultations in the clinic and the three in-depth interviews I have made with patients. Throughout most of this period (1990-1996), I was supported as a researcher by the postgraduate research group at Bath University but from 1996 onwards by my supervisors.

In choosing how my practice has changed, I have chosen to explore five themes;

- Inquiry groups and groups in the clinic
- Power and medical power
- The nature of expert knowledge
- Leadership
- How do patients judge quality.

I have chosen 'inquiry groups' and 'leadership' because part of my change in practice was an increased awareness of the importance of individuals other than the patient in influencing decision-making and understanding the clinical consultation. These include friends and relatives of the patient, as well as the presence in the clinic of other doctors, nurses or students. By reframing the clinical situation in terms of a group inquiry, this meant that an understanding of leadership/ facilitation became important as well. No examination of leadership/ facilitation is complete without a discussion on 'power', and as power is so intimately connected with knowledge, the nature of 'expert knowledge' was deemed important to consider as well. Finally, as a general validity issue, I was interested in how 'patients judged quality'.

The time frame of the story is not straightforward. If I had chosen to present this in strict chronological form, then my chosen topics of groups, power, leadership, expert knowledge and quality would be presented in this section of Reflective Clinical Practice concurrently with one another as my understandings developed. This would have meant jumping from one topic to another as the story unfolded over the last eight years. Instead I have chosen to take each of these themes and explore their significance as I came to understand them better. They each have a particular starting point. In the themes 'inquiry groups and groups in the clinic', 'leadership' and 'how do patients judge quality' I have used the entries I have made in the diary recorded whilst a member of the hospital inquiry group as a starting point for discussion. The topics of 'power and medical power' and 'the nature of expert knowledge' draw on clinical experiences as a starting point. Each of these themes is then developed to the point where I currently understand them as part of my practice. Explaining the story in this way has meant that I have placed the entry 'the end of the hospital inquiry group' towards the end of this section when in fact it ceased to meet in 1992. The sequence of topics, together with their subheadings, looks like this;

Inquiry groups and groups in the clinic

Patients and their relatives or friends
Other doctors in the consulting room

Power and medical power

Some broad schools of thought on the subject of power
Some selected philosophers on power
My position as a white, middle class, professional male

The nature of expert knowledge

Doctors as experts in their own illness
Patients as experts in their own illness
Children as experts in their own illness

Leadership

How do patients judge quality

End of the hospital inquiry group

I wanted to convey the sense that a series of frameworks evolved during the research as I developed as a qualitative researcher reflected by my progression from positivism to constructivism. I call these 'frameworks 1,2,3 and 4. To convey this sense of development, I have introduced them throughout the section. There is some sense in placing them where I do. Framework 1, at the beginning, is essentially a positivist approach, and seems to represent the starting point for this research. Framework 2 appears in the section on power and is relevant in this position because my development of this framework began when I appreciated that any framework, even one that supposes to be more equally distributive of power, is wrapped up in power issues. Framework 3, placed after the section on expert knowledge, was developed after recognising that my expert knowledge was theory and value dependant and so this framework emphasises the importance of all kinds of knowledge, qualitative and quantitative, in the clinical picture. Finally, framework 4, a position of espoused mutuality, is positioned at the end because such a framework claims to blur or abolish the distinction between researcher and researched and participator. It is the conceptual position as a researcher (theory about theory about data) that sees this framework development, from 1 through to 4, as representing a series of paradigm shifts. The final overall scheme of this section now looks like this;

Framework Type 1

Inquiry groups and groups in the clinic

Patients and their relatives or friends

Other doctors in the consulting room

Power and medical power

Some broad schools of thought on the subject of power

Framework Type 2

Some selected philosophers on power

My position as a white, middle class, professional male

The nature of expert knowledge

Doctors as experts in their own illness

Patients as experts in their own illness

Children as experts in their own illness

Framework Type 3

Leadership
How do patients judge quality

End of the hospital inquiry group
Framework Type 4

In this section I have drawn on clinical anecdote, experiences in the clinic, experiences in the hospital inquiry group, understandings obtained in the postgraduate inquiry group and the interviews with three patients to support my belief that change has taken place.

A little more needs to be said about these interviews I have made with patients, particularly in the way that they were made and the format in which they are presented in this section. Each interview was filmed on video and then a complete transcript was made. These interviews took place in chronological order. Each of these patients found themselves in a position where they had to make some difficult choices. David and Patrick had both been patients under my care. I was never involved with looking after Valerie but she has become a personal friend. All have given permission to include these extracts. The complete transcripts can be found in the appendices but each of them is presented in a slightly different way.

In the case of David, the text was cleaned up a little and many of the 'ums' and 'ahs' were removed. The bold numbers in brackets that appear throughout the text, represent pauses in seconds. The interview lasted forty minutes. The style of the interview is fairly structured and I ask questions that generally lead the conversation. David did not want to see the video or the transcript but always made it clear that he was very happy to talk about the issues that his difficult decision raised. Sadly, he died two years ago (1996).

For Patrick's interview a complete transcript was made, but on this occasion all the pauses (marked in seconds in brackets) were included, together with half words, repeats, 'ums' and 'ahs'. Patrick did not like the sense of incoherence this seemed to suggest and asked if he could clean up the text. He not only rewrote sections to make his position clearer, but he also added various observations and thoughts that he felt were necessary.

These have been clearly distinguished from the text. The pauses in the conversation have been left in place. The interview lasted two hours. It is much less structured than the interview with David.

In Valerie's interview I decided, given the experience with Patrick, that the transcription would mainly stick to the text and include repeats but not all the non-verbal utterances that occurred. Valerie's voice was very soft and so there were a number of moments when it was not clear on the video what she was saying. Valerie took the transcript and with the aid of her computer, rewrote sections so that what she wanted to say was clearer. Again, she added in various comments and when this has happened, it has been made clear in the text. The interview lasted ninety minutes. This interview is relatively unstructured. Whilst we started out with the intention of talking about the decision Valerie had to consider, much of the interview became devoted to a discussion about experiences in hospital.

In order to place these interviews and extracts in context, what follows is a short summary of the difficult position in which they found themselves.

David
Appendix 1

David, a businessman, was in his early forties when we first met. I subsequently saw him in outpatients on many occasions and at my request he kindly consented to a discussion about the way we had been working together. Two years before we had met, he had developed a cancer of the ethmoid sinuses, which are a group of sinuses located between the eyes and extending backwards to about the middle of the head. The initial treatment offered was fairly straightforward and took the form of a course of radiotherapy consisting of daily visits to the centre for a period of six weeks. The side effects were relatively mild and a CT scan (detailed X-ray analysis) of the sinuses revealed that, as far as could be ascertained, the tumour had completely responded to the radiotherapy. All seemed well for about 18 months when a recurrence of the original symptoms suggested

that the tumour had returned. A biopsy of the suspected area confirmed that this was the case. This was the moment when we met for the first time.

The dilemma now facing David was a fairly classic one in head and neck malignancy. No further treatment with radiotherapy was possible so that, broadly speaking, there were only two alternatives. By declining further treatment, he could accept the inevitable outcome of death and survival was estimated to be a year or at the most. The plan would be to continue to 'live in the fast lane' (David's words) until the return of uncontrolled symptoms made this impossible. Alternatively, he could undergo major surgery. This would be extensive and involve the removal of all the diseased area between the eyes, but would also include removal of the left eye. There would be a significant risk of operative mortality, perhaps 5%, and a considerable period of disability, discomfort and tiredness during the time in hospital and afterwards at home. This might last for as long as three or four months. The degree of disfigurement would depend a little on the final surgery but was likely to be modest. The chances of a cure would be no more than about 10% but if the tumour were successfully excised it was possible that he may experience a normal or near normal life expectancy of good quality. He chose to leave the tumour untreated and continue with a near normal life for as long as he could. I interviewed him about eighteen months after he had made this decision. The purpose of the interview was to discuss how he had come to make this difficult decision and to hear his views were about the way I had worked with him as a doctor.

Patrick

Appendix 2

Patrick was in his early fifties when I first started to look after him. He had developed a tumour in his neck. Tumours in the neck usually present as a result of primary in another site but, as is sometimes the case, no other primary could be found. A few years previously he had had a testicle removed because of a malignancy but this was not thought to be the related to the current problem. The glands of the neck were removed and he underwent a course of radiotherapy to the neck and to the back of the nose, a site

known to be one that can harbour a very small otherwise undetectable primary. All seemed well until two years later when he decided to have a small cyst, which had been present for twenty years, removed from the top of his scalp. Another surgeon undertook this procedure. To everyone's surprise this was reported to contain a small primary tumour, which was thought to be probably the source of his original neck tumour. There were two choices here. It was possible to have further radiotherapy to the area on his scalp as a kind of belt and braces approach to be sure that all the tumour had been removed, or alternatively to wait and watch the site carefully for any kind of recurrence. Patrick's faith in the infallibility of doctors had been shaken and so this was a decision he felt inclined to make for himself.

In this case there was an additional awkward issue for me. When we had first met and found the tumour in his neck, we had discussed the arguments for and against removing the cyst from his scalp. It had been decided to leave this alone but subsequent events had suggested that this was an error. The purpose of the interview, from my point of view, was to talk about how he had made the decision when he had lost considerable confidence in doctors and his reactions to the way I had been involved in his treatment. Patrick also wanted an opportunity to talk about his feelings during this difficult time for him.

Valerie
Appendix 3

Valerie is in her early fifties. Unlike the cases of David and Patrick, I have not been involved in her care. She started to experience problems with her health from her late teens onwards. Throughout her adult life, she has experienced a progressive loss of lung function and the point has been reached where she has to make a decision between two choices. Either she could continue to make the most of her deteriorating lung function or opt for a heart lung transplant. Without such treatment her life expectancy was thought to be about ten years but the heart lung transplant carried with it short term risks of failure and longer term problems of organ rejection. Her position was complicated by the fact

that she has a brain cyst and has experienced epileptic episodes. The remarkable thing about Valerie is that despite such difficulties, she leads an independent life and occupies a senior position in the arts world.

The purpose of the interview, from my point of view, was to discuss the difficult decision that Valerie was in the process of making. The rather open, unstructured style of the interview, meant that the interview turned to some of the experiences the Valerie had had in hospital, together with some of her thoughts about the nature of chronic illness.

Framework Type 1.

Framework 1 seems to me to represent the obvious starting point. This decision making framework is one I would regard as the 'traditional' one, in which the doctor observes the patient, examines them and offers treatment. For this reason I have given it the subtitle Observer/Healer. What is meant by this and how does it work in practice?

Observer/healer

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator

The doctor observes and researches the patient but the patient acts as observer/participator. In this situation, a doctor will take a history, observe and examine the patient and then, with little or no reference to the patient's own perspectives, suggest a treatment. The frame in which such the medical problem is viewed, disregards context. The doctor assumes that he or she can select the most appropriate treatment for the lifestyle of the patient. It is technical and directive. Such behaviour is acting at the level of technical rationalist and represents treatment applied in the positivist paradigm. It is presented in simple diagrammatic form in **Figure 4.** Before commencing this research,

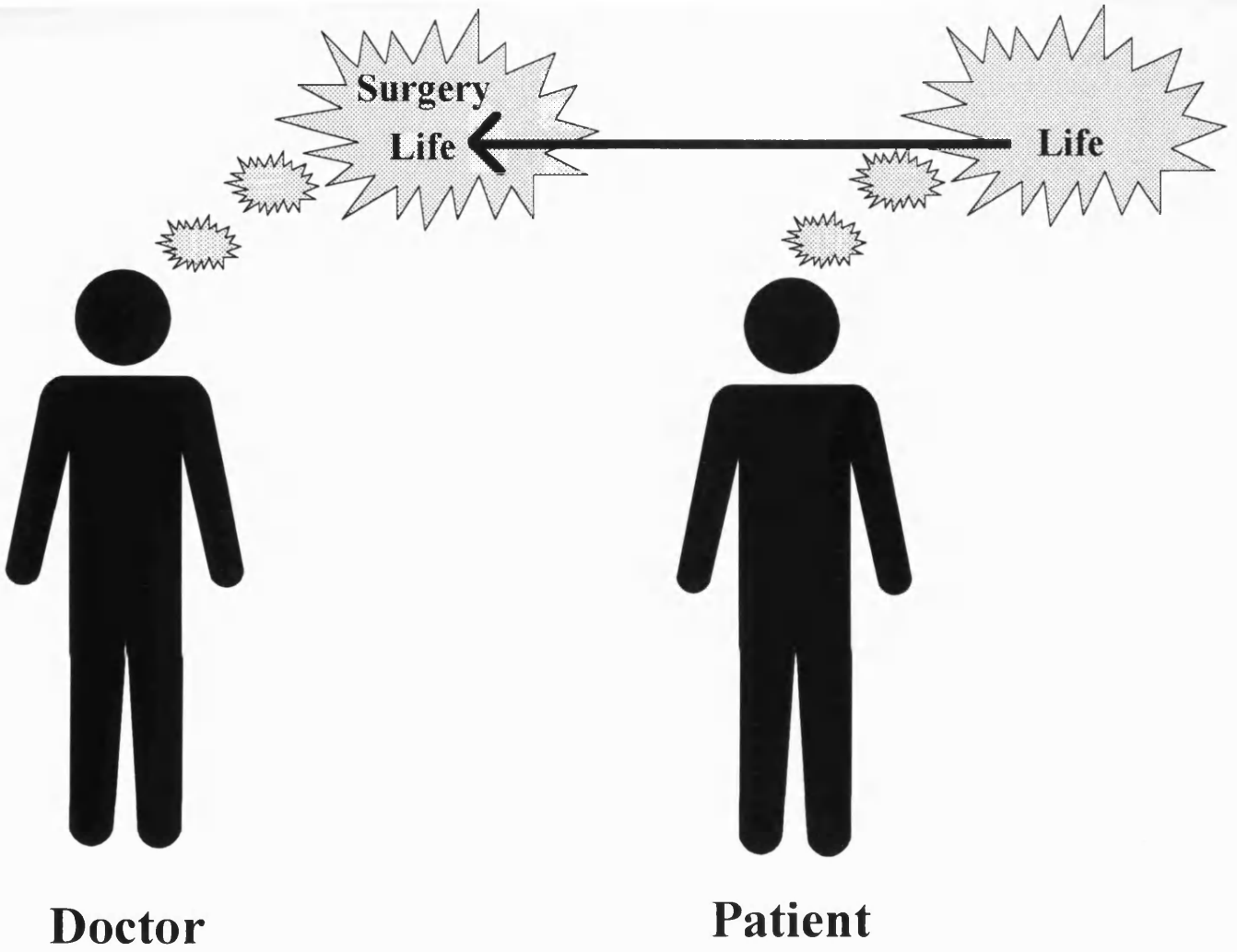


Figure 4. Type 1 The Observer/Healer

In this framework the doctor observes and researches the patient's medical problem and then determines treatment.

Inquiry groups and groups in the clinic

The first diary extract comes from the first meeting of the Hospital Inquiry group, which began to meet in October 1990, the same month that the Postgraduate research group at the University of Bath started to meet. The Hospital group was set up with the idea of developing a co-operative inquiry group into clinical decision making.

The group was formed to research the Head and Neck Malignancy Clinic, with the espoused purpose of trying to improve the way it was run for both patients and doctors. During the course of these Hospital Inquiry meetings, many new and unexpected points of view emerged, which began to make me re-evaluate the perception of my own behaviour and my perception of the behaviour of others. In particular, these meetings began the process of alerting me to the level of inference in which I was operating. The group provided some opportunity to provide feedback that challenged the way I had progressed up the ladder of inference, from directly observable data, to cultural inference to theoretical meaning (theory in use) without first testing the validity of this position at each level. (Argyris, Putnam, et al. 1985 p345) This helped to initiate a process of self-examination that alerted me to inconsistencies in my own reasoning about any given situation. As the following extract will illustrate, this was in a way that confronted me, because my perception of the Head and Neck clinic was very different from the perception of some of the other members, an interpretation that I call "hostile". Confrontation like this may have been useful. Argyris felt that sudden confrontation of this sort often helped to "unfreeze automatic behaviour". (Argyris, Putnam, et al. 1985 p349) Nevertheless, my initial reaction to what I call "hostility," is partly open, because I do not attempt to suppress it, and partly defensive because I interpret it as my fault. My suspicion is that my reaction might have been considerably more defensive but for my participation in the University Postgraduate group.

These extracts have not been altered other than a little editing in the interests of clarity. For the first entry, a little more than is perhaps necessary for the discussion of the

subsequent topic of 'groups' has been included to convey a little of the flavour and variety of what was being discussed.

Diary from Hospital Inquiry Group. 7th Oct 1990
1st meeting. Attendance: M, Female House Officer; C, H(Part Time), K, A, Female Senior House Officers; G, Female Registrar; K, Male Senior Registrar(SR); Self.

The most striking feeling I was left with after the meeting, which lasted 50 minutes, was the hostility generated by talking about the clinic. Words such as 'intimidating', 'exhausting', 'the worst clinic I have ever attended', 'terrible for the patient' were typical. It seemed clear to me that a clinic in which literally life and death issues were discussed sensitises us all to the issues and generates much anger, resentment etc. at perhaps having to face the issue of our own mortality. I couldn't help feeling that most of the anger was directed at me. To some extent I think that this was inevitable since I feel sure that I am perceived as 'responsible' for the clinic and have undoubtedly been the one who has attempted to draw them all in and involve them in the discussions that take place in the clinic. If they have been feeling uncomfortable being there in the clinic, such a practice is bound to create hostility. This attitude from them encouraged me to avoid leading the group discussion and I think I began to detect signs that this was starting to work. In the last 5 or 10 minutes individuals were starting to address each other rather than direct all their comments toward me.

The question of group control and meaningful direction is crucial. I can see that there is a delicate balance between three forces, which are to some extent opposites. Firstly a free and open discussion, secondly some kind of direction and thirdly an element of leadership without alienating the sense of collaboration. I suspect that the idea of some leadership will be an anathema to some collaborative inquirers, but at this early stage it seems that the risk of drifting, particularly with a group of doctors who are probably all 'goal orientated' in approach is too great. The whole thing could easily founder.

As the session progressed, a sense of purpose started to spontaneously develop. We talked about the goals of a head and neck malignancy clinic and it became clear that the next meeting, a month later in November, should devote itself to considering a small change in the way the clinic was run. We could then assess this change in the following clinic in December.

The question of gender arose in particular in relation to women being more sensitive to the feelings of patients. This disappointed me somewhat as I don't like to be personally categorised and categorised into an insensitive group at that.

After the meeting, two of the group independently approached me asking if they could form a separate group but with patients, who have been through a clinic, to explore how they felt about the experience. It had occurred to them that this exercise was exploring their own anxieties and that this may bear no relationship to those of the patients.

The emotional content of the meeting, what I called 'hostility', illustrates some of the demands of free and open inquiry. Argyris summarised these demands in the following way: "Participants must be able to retrieve largely tacit inferential processes...they must be able to deal openly with challenges and conflicting views...they must reveal information that might expose their own or other's vulnerabilities; they must be able to recognise and acknowledge when they are wrong... they must feel free to choose among competing views." (Argyris, Putnam, et al. 1985 p238) Such requirements, he maintained would "foster learning" but ran the risk of generating "disagreements, conflict, embarrassment, and failure, evoking defences to minimise such risks." (ibid) My own approach in feeling that "much of the hostility was directed at me" and my own reluctance to defend the idea that I thought the clinic worked well in a number of ways, suggested a somewhat defensive reaction to this point of view. In terms of inquiry, there are several ways to approach such feeling. Argyris would advocate a more introspective, process-orientated approach to encourage the participant to "focus on individuals' emotional reactions" so that "we can more fully grasp what individuals are up against, as well as how they manage such reactions." This may be problematic because to "to

publicly retrace and make public these processes involves risks that themselves evoke emotional and defensive reactions that hinder the retrieval of these processes and make it difficult to report them to others." (Argyris, Putnam, et al. 1985 p246-247)

Torbert might see such attitudes as representing commitment, on the part of the participants, to a principle. Torbert took the view that it is often appropriate to hold onto one's own belief with conviction in the face of criticism, for a number of reasons. For him, it enabled ideas and convictions to be communicated that he was otherwise unable to, it eradicated nervousness and anxiety in expressing strong feelings in public and it created a group norm "that permitted open, strong disagreement". In addition, "because the argument had been so surprising to everyone and so positive in its outcome, it created a norm of welcoming surprising new directions" (Torbert 1991 p137-138) Such a strong feeling on the part of some of the participants might have enabled them to overcome "their nervousness", and in doing so help create a norm of more open inquiry if that is what is perceived to have happened.

This early experience in the group were helpful in beginning to explore discontent, dissatisfaction, sadness or even hostility as a process issue in the clinics. Instead of adopting a posture in which these feelings were denied or glossed over, I would consider as a researcher, whether it was appropriate to inquire into their meaning. Earlier in this thesis I gave an example of how, when encountering difficulties discussing a tonsillectomy that had nearly ended with disastrous consequences, it had become liberating when we shifted emphasis to discuss the possibility that the medical staff might be covering up a mistake. Such an approach has been made possible by "focussing on individual's emotional reactions." Such an approach might be expected to make the consultation anxiety making and I found it stressful because it does not seem easy to ask such questions when it seems safer to stick to a medical discourse and talk about bleeding, blood gases and the like. If such interventions, stressful though they seem at the time, lead to a position that was perceived by myself and the patient (through inquiry) as worth exploring, then I took this as evidence that validated this approach.

When I consider that the Hospital Inquiry Group was drawn from every hierarchical level of hospital medical life, from consultant, registrar, senior house officer, to newly qualified doctors of only two months experience, it did surprise me to see individuals apparently talking so freely. In my experience in hospital, both as a trainee and as a consultant, I had never encountered a group of trainees and consultants together who had had quite this kind of conversation. One reason may lie in the fact that a significant number had previous experience of this kind of discussion group because it forms part of the training for most general practitioners, but not for surgeons. Whatever the cause, it certainly seemed that those taking part were motivated to interact. What was the key to this interaction?

Randall and Southgate maintain that; "The key to any interaction, whether it's between any two people or in a group or organisation is DESIRE. The first question to ask when looking at a group is-What do it's members desire?" (Randall & Southgate 1980 p2) Questions like this certainly draw attention to some assumptions that I have made. My interpretation that they felt a freedom to discuss openly what was happening represents an assumption about behaviour, a process issue, and my observation about motivation represents an assumption about purpose. At the beginning, I had assumed that the members of the group would share my interest in decision-making, or at least would enjoy the opportunity to take part in such a discussion. This high level of assumption meant that I didn't take the opportunity to ask other members of the group what it was they desired. Did this matter? Would the question itself have been meaningful?

This question cannot now be answered, but work has suggested that straightforward questions like this do not always lead to straightforward answers. Sometimes members of a group will respond to a question like this by offering the 'official' reason for being in such a group? "Most groups have an 'official' desire. This is usually given as the reason for the group's existence. Sometimes it is more of a theory about what people in the group ought to want or desire."
(Randall, R. Southgate J. 1980. p16)

Members in a group may have actual, official or private desires to be part of a group. This complexity suggests that the 'desire' to participate in a group may be pluralistic. In the creative group actual, official and private desires are united but, more commonly, there is an intermediate position in which there may be conflict between these various desires but the group still continues to exist. If this is not considered or negotiated properly, it may make a considerable difference to the subsequent creativity of a group. "In the destructive group, the levels of desire are split. The actual, official, and private desires are swallowed up, or swamped by the desire to survive at all costs." (Randall, R. Southgate J.1980. p19) In the Hospital Inquiry group, the 'official' reason for existence of the group was to engage in an exploration of decision making because that was how I had set up the group. Was any attempt made at the time to explore the actual/ private desire of the group members? Sadly, the answer is 'no' and it is no longer possible to retrace this process, but the question can prompt me, as a researcher, to ask about my own 'actual'/ 'private' desires for forming a group.

I believe I can see that one 'private' desire on my part was to find a group that would provide a forum for practising facilitation and developing inquiry skills. After watching facilitators in the Postgraduate group, I could practice these skills in the Hospital group. At the time my 'espoused' theory was to start a collaborative inquiry group, and this may have been partly true, but 'my theory in use' may have been to start a group to practice facilitation skills. This eventually became clear as my methodology developed and I began to pay attention to the purpose of each of the groups; a point I will address shortly.

The need to develop facilitation skills raises a number of questions that concern the nature of initiating an inquiry that go beyond research question, epistemology, methodology and ethical stance. There is the need to address practical issues. There is the need to energise it, the need to generate shared purpose, and the need to negotiate the relative roles of participator, researcher, leader or facilitator in this environment. Torbert asks, "What kind of leadership and organisational structure integrates the apparently incompatible qualities of shared purposiveness with self direction, of high productivity with confrontative inquiry, and of both pairs with one another?" (Torbert 1991 p7) Some

Table 1

Fives stages of Group Development and the Leadership Style after Neilsen.

Stage	Nascent Structure of Group	Relational Issue	Core Dilemma	Needed Leadership Style	Needed Influence Behaviours
1	Each person for him- or herself	Inclusion	Safety versus anxiety	Directive	Commanding, prescribing, legitimizing
2	Dyads	Inclusion and influence	Simmilarity versus dissimilarity	Coaching	Instructing, debating, bargaining
3	Coalitions and cliques	Influence	Support versus panic	Participative	Involving, committing
4	Connected coalitions and cliques	Influence and intimacy	Concern versus isolation	Appreciative	Nuturing, applauding
5	A single integrated group	Intimacy	Interdependence versus withdrawal	Inspirational	Innovative challenging

(1986. Neilsen. p85) After Srivastra S, Obert S.L., Neilsen E.H. 1977

more participative/ appreciative in a more mature group. (Neilson. EH. 1986. p85). This suggests a transition from a more 'energising' approach in the early stages to a more collaborative inquiring approach in a group that is more mature. For example, a more participative style of leadership might have acted upon the idea of forming a patient discussion group, suggested by the two members at the end of the first meeting. In the course of time, this involvement of patients from the beginning may have lead to a genuine co-operative inquiry group. On the other hand, clear direction may have been needed because otherwise it might have resulted in loss of intent, direction and form, particularly as this group was one whose members changed every six months when trainee staff rotated to other posts.

Torbert extends this notion of attention further by suggesting that leadership involves having a clear grasp of the importance of the following 'territories;

Intuitive mission
Rational strategy
Behavioural operations
Tangible outcome

He put forward the idea of "a paradigm of just action" that saw "the need to cultivate an awareness that embraces the realms of the intuitive whole, the rational strategy, plan, or rules, congruent action, and outcomes *that observes and corrects errors and incongruities from one realm to another."* This involves a simultaneous awareness of each of these four territories of experience. Attempts to achieve this are linked to a hierarchy of leadership development that progressed from 'impulsive' to 'ironist', whose "governing frames determined behaviour in terms of mission, strategy and behavioural operations" in the following manner. This has been referred to in an earlier section but the list is reproduced here for convenience.

Governing frames at successive developmental stages

Stage	*Name*	*Governing Frame*
1	Impulsive	Impulses rule reflexes
2	Opportunist	Needs, interests rule impulses
3	Diplomat	Expectations rule interests
4	Technician	Internal craft logic rules expectations
5	Achiever	System success in environment rules craft logics
6	Strategist	Principle rules system
7	Magician	Process (interplay of principle/action) awareness rules principle.
8	Ironist	Intersystemic development awareness rules process

(Torbert 1991 p42-43)

Such a hierarchy, where "each succeeding construction 'dethrones' the assumptions of the previous construction" suggests a progression to a wider reality that is necessarily more appropriate as well as desirable. One is left asking, where would I place myself or be placed by others? Is there room for a level of leadership that can change depending upon context? What kind of leadership is appropriate for a surgeon in a group, in a clinic?

My recollections of what I was trying to do at the time were focussed around the business of trying to empower the trainees in the department to feel as though they could, as well as ought, to contribute to a debate about the merits or otherwise of the clinic. My comment that I feel that I have been the "*one who has attempted to draw them all in and involve them in the discussions that take place in the clinic*", would seem to indicate this. This wish to 'empower' them was to some extent reflected in the way that I started to act organisationally in the day to day running of the department. I suggested that they organise their own rota, start to construct their own educational programmes and organise their own working week to staff the clinics and wards. I perceived that the act of removing power from myself was equivalent to empowering them. In fact, as later diary extracts will testify, in some ways the department began to fall apart and there were occasions when things went distinctly awry. Torbert experienced much the same thing:

"In my own early attempts as an adult at leadership of socially innovative organizations, I exercised power as little as possible in order to empower others. Only upon reflection afterwards did I begin to realize that these situations had required a greater exercise of

power (at times unilateral, at times logistical, at times transforming), and that what I had in fact enacted and thus modeled for others was *not* exercising power. My self-empowerment had contradicted my espoused aim of empowering persons. To make matters worse, I discovered that a large proportion of my co-workers tended to assume that I was utterly naive or that I was mysteriously devious and manipulative, my self disempowerment had powerful and negative effects on others."
(Torbert 1991 p69)

Torbert does not supply any data to support this view, but I have on occasions sensed the same thing. In preparing this section, I asked a good colleague and friend for an honest account of how he perceived the way I exercised power in the department. His considered reply was that whether or not I was actually doing this, I gave the impression that I was always trying to think two or three steps ahead of what was happening and that this sometimes conveyed a sense of 'deviousness', almost the same expression used by Torbert. .

Where does this put me in the leadership hierarchy of Torbert? I cannot begin to answer this but as a researcher, I am struck by the need I have to try and find an answer to this question. What is at stake here? Is this leadership hierarchy a means whereby I can measure achievement, how my understanding of the world exceeds that of others with whom I work? If I apply Torbert's own four territories to this question and ask myself what is the intuitive mission here? What is the strategy in writing about it in this way? How is it going to alter my behaviour and what can be achieved by this discourse? The questions themselves seem to evaporate. I am left with the residue that the concept of leadership styles expressed in this way is useful but that it may not be useful to apply them too conscientiously to any given situation. As Marshall says; it may be useful to adopt a "more playful touch". (Marshall 1992)

Randall and Southgate offer a different analysis to group development and leadership styles. It is much less dependent upon the actions of the single facilitator/ action inquirer than Torbert's approach seems to imply. It looks at the different roles that may develop as

a group matures. If sufficient attention is paid to doing these roles well, then the group will be productive and cohesive, but if this is not done, then the group may be destructive. This outcome is not necessarily regarded as failure, it just produces different kinds of data. The analysis itself is more attuned to the participatory paradigm. They define four phases in the development of a group; nurturing, energising, peak and relaxing. Three types of leadership quality were displayed in this early nurturing phase of group development; organising, production and emotional. (Randall & Southgate. 1980. p24). Organising leadership is interested in information gathering and alternative ways of looking at problems. Production leadership concentrates on preparation for the task and emotional leadership pays attention to emotional support needed by members of the group and maintaining a sense of group cohesion.

It is very tempting to look at clinical practice re-framed in this way. I would suggest that medical education equips a doctor reasonably well for the tasks of organising and production leadership. The interest for me lies in the requirements of 'emotional' leadership in the clinical situation and how to pay attention to such issues satisfactorily in a brief encounter. If the idea that an outpatient consultation can be considered as a 'group' is sustained for a moment, what are the emotional leadership qualities displayed as a group develops? According to the model put forward by Randall and Southgate, the task of the emotional leader is not static but changes as the cycles progress through the four phases of a creative group.

Group Phase	**Emotional Leadership Quality**
Nurturing	Emotional support, group cohesion
Energising	Fire the group with energy
Peak	Leadership not important
Relaxing	Task winding down

In looking at this sequence, I ask myself what role, if any, do I play here in the clinic and is this theory relevant given that the 'group' meeting is so brief? In considering this question I began to notice that I spend a great deal of the time reassuring patients that there is nothing wrong, so much so that I am often struck by how much anxiety the

medical profession is capable of generating. As a young trainee in general surgery I remember seeing endless terrified young women with breast lumps, all fearful that they had cancer. In reality very few of these lumps were found to be malignant and so the vast majority of patients were reassured that all was well. This meant that there was a sequence of generating tension with the history, examination and aspiration cytology, which was usually relieved by the good news that the results were normal. I began to notice how pleasurable it was to give such good news to many, who were expecting the worst, and so it was not uncommon for patients to spontaneously hug the doctor with relief. All this tension and relief appeared to be medically managed.

I began to reflect on the manner in which anxiety was managed in the clinic and noticed a pattern of clinical practice. In a clinic a doctor has only a few choices he or she can make. They can discharge the patient, investigate the problem or, in the case of a surgeon, list for surgery. Justification for investigating a problem often rested on the suggestion that something more serious was possible. This action lent purpose to the visit for both the doctor and perhaps for the patient as well. Ruling out something serious felt like a worthwhile role for me to play. It reinforces the notion that I am there to investigate serious problems. Many authors have commented on this strategy of physicians to promulgate an image that "at any moment they are involved in lifesaving activities. This is reinforced, especially in hospital clinics, by an atmosphere of alarming noises emanating from loudspeakers and intercoms implying that somewhere a life is being saved." (Taggliacozzi D. et al. 1972.) I cannot be sure but from the reactions of patients I suspect that the decision to investigate was perceived as justification for coming.

The following is a simple example of how all this might take place in practice. "At some point you must have wondered about a brain tumour. I really don't think this is at all likely but we ought to be absolutely sure and rule it out, all the same. Just to be on the safe side, let's do a brain scan. Don't you agree?" A brain scan would be organised and the patient would then return for the results. In the vast majority of cases the test would be absolutely normal and the patient would be reassured so that this strategy is almost

failsafe. At the end the patient would feel better, and I would experience professional satisfaction by such reassurance.

The very large number of normal laboratory and radiological results seen in clinical practice may be testimony to the frequency and self-sustaining nature of this approach. After routine examination for insurance or employment, three quarters of the patients were referred for exclusion of heart disease, suggesting that unjustified concern about ill health was often iatrogenic. (Fitzpatrick R. 1996. p311) McDonald and Mayou both reported that a third of patients still continued to be anxious after an investigation revealed a normal heart. A similar study of headaches and reassurance about serious disease revealed a similar picture. (McDonald. 1996. p329; Mayou R 1976 p55; Fitzpatrick R. 1981. p1067). The process of reassurance generates further anxiety and a further appliaction of the same process.

As a researcher I find myself asking, whose interests are served by such an approach? The patients? Mine? If 'good clinical practice' is perceived as the espoused theory, 'interest in generating anxiety and subsequently relieving it' might well be the theory in use. In order to inquire into this I began to change my practice in such a way that explored the question 'whose interests are served here?' After taking a history from a patient, who was dizzy, conducting a careful examination and performing a simple test or two, I might then chose to explain the issues here in the following manner.

"I do not think that you have a serious problem. I have taken a detailed history and carefully examined you with this in mind. I am not infallible and there is a very small chance that there is something more significant going on but the only way we can be absolutely sure would be to do a brain scan. This involves not inconsiderable exposure to radiation and so it is a test that is not without hazard. I am perfectly happy to leave things as they are and not do these tests, but this is a decision in which we have to take some collective responsibility. Would you like to say what your feelings are on the matter?"

Some would chose to be investigated but the majority of patients, when presented with information in this manner, chose to have no further investigations. Furthermore, they not infrequently indicated that they appreciated that this position was made clear in this way. This outcome suggests that my theory in use is concerned with protection and reward. The protection lies in lessening the chance of missing something diagnostically and the reward springs from raising anxiety in the patient and relieving it with a series of normal investigative results. Torbert might regard this as an analysis based on switching attention from strategy to purpose and raising the level of inquiry around purpose.

Groups in the clinic.

As time went on, I began to notice the existence of various other groups in the clinic. I had previously perceived the clinic as a doctor and a patient interacting, with a variable number of others, both medical staff and patient's friends and relatives, looking on as observers. Discussions in the Postgraduate Research group and the Hospital Inquiry group led to a re-evaluation of this position and I began to reconsider the clinic as a much more complex collection of different groups within groups. For example, it meant regarding the patient and his or her relatives or advocates as a distinct group. Other doctors and/or medical students, who may be in attendance for training purposes, form another group. Finally, coalitions between the patients and these other doctors in attendance form yet a third group. Is re-framing the clinic as a group encounter with these coalitions useful in the clinical context?

An outpatient consultation, involving only a doctor and a patient, represents, in number terms, the simplest of groups. On many occasions other people may be present as well. What is the effect of more than two individuals in the consultation? What if a small group forms in outpatients? How is it influencing the kind of issues that are raised? Is it permitting some issues to more easily emerge in the same way that I suspected had occurred in the inquiry group of doctors and others or does the inhibiting effect of being part of a group create more problems than it solves?

There are many possibilities in terms of numbers of doctors, patients and their relatives that may be present in the clinic. For some of the time I will be the only doctor with a single patient but I sense that it is becoming more common for patients to come with an 'advocate' such as a close relative or friend. Children will nearly always be accompanied by a parent, frequently both, and at times with one or two siblings as well. Adolescents often bring along a 'friend' just to sit in. I may not be the only doctor. It is usual at the Royal United Hospital, Bath to have one and sometimes two trainees in attendance, and from time to time a medical student. When I first showed some of the video of outpatient consultations to the Postgraduate Group one of the first comments to be made was surprise at the number of people in the room; other doctors, nurses, parents, relatives and friends. The influence of these other groupings has been shown to be very complex and frequently extends beyond the apparent main players, as one particular example shows. "Data showed that the discussion was likely to be initiated by a professional outside the patient's household, that the number of actual participants in the discussion was small, that social network--friends and relatives--were important during the communication and discussion processes, and that the decision to enter hospice care was likely to be made by the caregiver.....as well as how social networks, particularly friends and relatives, who all serve to communicate information about hospice."
(Gochman D S. 1990. p15)

Indeed 'David' had talked about the time when he had decided to have no further treatment and experienced the need to try out such a decision on his friends.

"D: Huhh. Ac', actually it was a fairly amusing time for me (laughter), I know that sounds ridiculous but it was. When we left here, Linda was in tears and she was very, very upset, she didn't know where she was going to go and I said come on, I'll buy you a drink and we went down to the pub, got, got her a stiff drink and I had one, came out and got in the car and she said you've not fastened your seat-belt up. I said well I don't do things like that anymore. She said what do you mean, you're breaking the Law. I said, well

(1) there are no laws really, if I'm going to shuffle off in a year I'm now going to bloody well please myself for a year and we went home and we had the first of my 'Dave C's Dying Parties'. Rang round all the friends and said uhh (laughter), said that's it lads, if we're going to shuffle off you'd better all get round here and uhh literally within an hour of having left you, I'd got a house full of people and we had an enormous piss-up that went on 'til about 2 o'clock in the morning. Everybody had a fabulous time and uhh (1) I think in a way that was my way of breaking everybody into the news and getting them laughing and looking at it in the right sort of context in a light sort of way rather than uhh being told in hushed tones that C's on his way out. (1) And I think again (.) the circle of friends that I have helped me enormously because they didn't sort of walk round talking in hushed tones and they weren't you know sort of talking behind back hushed 'How is he today? and all the rest of it'. "

(Appendix 1, David)

During the course of the discussion I had with Valerie, she indicated that she undertook the same kind of process.

V: That's an interesting one because that's what I've got to do about the transplant in the end. I have a friend whose daughter, who's one of my very, very good friends and who's been great support to me for some years her daughter is a councillor with London Underground. So when I went up to London to be assessed for the transplant, I actually, I asked her if she'd come and see me and I said 'how do you decide between two things that seem as bad as each other? Because I mean the time that Professor Z was giving me, not that I realised this then, and the kind of death he's described, is not that significantly better than the transplant except that of course it's much less invasive. But basically I asked her 'how do you decide between the two things, neither of which is very attractive?' And umm she came down in the end to something that .....

R: She said?

V: to obtain all the information you can about both, you know, both treatments.

R: Yes.
(Appendix 3, Valerie)

My experience with groups meant that I started to re-examine what was happening in outpatients. Rather than ignore the existence of others in the room, I started to pay attention to their presence and reflect on what their presence might mean. In one sense, a visit to outpatients by a patient, accompanied by relatives or friends, in the presence of a doctor, with or without colleagues or medical students is rather like the first meeting of an inquiry group. If it is regarded as a one-on-one interaction between doctor and patient with an audience of relatives, friends and colleagues, then important information may be lost. Can an approach that considers the clinical consultation as a complex group shed any light on what might be happening?

My interest in re-framing the clinic in this way arises from an interest in how opinion from one party (the parent in the case of the child; the relative or friend in the case of another adult) can be seen to justifiably enter the decision making process. If the patient is considered as an independent entity, the part played by others in influencing outcome has no point of entry. Such a perspective also obliges me to consider the influence on other patients and myself in the clinical environment. Much of what follows springs from re-framing the clinic in this way. In doing this I have considered three cliques or coalitions as Neilsen calls them. These are the connections that patients make with other relatives or friends; the connections which doctors make with other doctors or medical students who may be present. Finally there are the connections that accompanying doctors make with the patient.

Patients and their relatives or friends.

About forty percent of my practice involves seeing children with Ear, Nose and Throat problems. When children attend a clinic they usually do so with a parent. Usually they will attend with their mother, sometimes with their father, sometimes with both parents and brothers and sisters attending. Occasionally they may be with childminders,

grandparents or an older sibling. Do these different patterns of attendance mean anything?

The patient and their relative(s)/friend(s) would form a coalition between themselves so that I make the assumption that this is already mature. Neilsen has advocated that such dyads and cliques allow inclusion *and* influence and my experience in the Hospital Inquiry group had suggested that this can happen. I began to look for evidence of such coalitions and cliques in the clinic. For example I began to more carefully notice who came with the patient and wondered if such advocates acted as a chaperone, as an acolyte to balance perhaps the acolytes of nurses and receptionists surrounding the doctor. I proposed earlier that the ceremony surrounding outpatients of journeying, waiting, ushered here and there by 'courtiers' and undressing was partly a device to empower the doctor and disempower the patient. If the patient arrived with their own coterie of 'courtiers' this might be seen as a device to rebalance this distribution of power and I couldn't help but conjure up a picture of a medieval dignitary arriving at court with their own dignitaries. I began to observe that these 'courtiers' would hardly ever come in first unless it was a parent accompanying children. It would be usual for a husband or partner to hold any coats, bags etc. and somehow this seemed to immediately establish a role for themselves, a reason for being there, a legitimate reason for being there. I saw this as mirroring the nurses who held instruments, diaries, notes, all the trappings of my trade.

Most attendees would remain quiet, occasionally volunteering information. They might reinforce, with little sounds, shifting of position, repeating statements, certain key points as the patient made them. Patients might turn and look at them for emphasis, to gather support. It appeared to be a way of gently indicating the presence of a dyad or coalition and that was certainly the effect that it had upon me. Finally, they may take over in part or in whole the patient's role in the consultation. This is very reminiscent of the behaviour described above when 'C' started to first voice her disapproval about certain aspects of the clinic.

Such a description tends to suggest that any liaison between a patient and a relative or friend was always a collaborative one. On some occasions a patient might choose to decline the services of a friend or relative. A patient might firmly indicate to their relative, who might be making motions to enter the consultation room that they should remain outside. The empowering effect of this seemed tangible. The patient appeared to convey an impression of authority. This felt exactly like dismissing one's own 'courtiers'; it seemed empowering to the patient. This was enhanced even more when, on the rare occasions that it happened, the patient chose to dismiss my courtiers and asked other doctors and nurses in attendance to leave, so that only the two of us remained in the room.

Such groups within the group could be regarded as having different degrees of maturity. A family group might be considered as a robust *coalition* at the level of stage 4 (see Table 1) and as a well established coalition claim the authority to have a marked influence on the process. This can be seen most obviously when parents conduct the whole interview without any opportunity for the child to contribute, indeed they may have to if the child is in infancy. This may even happen to children who are teenagers. It appeared to me that the child seemed perfectly content with this arrangement when I took the opportunity to ask if this was so. A less mature coalition of adolescent and friend would be more like a lower order *dyad* and the friend might expect only a modest degree of inclusion. My feeling was that they were there to empower the patient, their friend, in a way that made them comfortable. This is certainly the argument made by Neilsen, who advocated that these coalitions are believed to be helpful in resolution of the core dilemma, which is, in most cases, likely to be the level of anxiety felt by the patient.

I began to ask whether the accompanying persons were relatives, or parents, or friends. This led me to ask why a partner, wife or friend, had come with the patient. This was met with a number of different replies.

"because I was/they were asked to come."
"I was nervous and needed some support"

"I never remember what is said and someone else can help me to remember"
"Someone to talk to afterwards if I have a difficult decision to make"
"Someone to talk to if I am given bad news"
"My friend was curious "(common amongst adolescents)
"I hate hospitals."

The variety of answers meant that it was unsafe to make any assumptions about why relatives or friends had decided to come or why the patient wished to be accompanied in this way. It did mean seeing the group of doctor, patient and advocates and other attendees as a collection of coalitions each with their own *reason* for being there. If their attendance, and mine for that matter, was seen as *strategy* then it was important to consider the *purpose* behind it. Why was everybody there, what was their individual or collective *desire* in being there?

As Randall and Southgate have maintained, this is important to consider if one is interested in establishing a constructive, creative group, for in one way, this is exactly what my perception of an outpatient consultation began to be. This meant paying attention to 'agenda setting', particularly patient agenda setting. It meant creating an opportunity for patients to put forward a reason for being there, an espoused reason albeit. I saw this as an attempt to establish purpose and desire. About this time I began to explore more fully expectations and frame the consultation with questions such as "What are you hoping to get out of seeing me today?", "What is your purpose in coming today?" This was sometimes developed to include a range of extreme choices indicating that any choice within these extremes was in order; for example "Do you want to go back through the door with an operation in the book or definitely avoid one?" Such an approach seemed to prompt patients towards a position where they could use me more effectively, because their reason for coming, wanting to leave etc were made clearer by an opportunity to declare their 'interests'.

This approach resulted in surfacing some of my own experiences of illness in the family. I began to recollect how it felt when purpose and interests and agendas as associated

family members were ignored in favour of apparent purposes and interests and agendas of medical agency. Certainly no apparent attempt was made to distinguish them from one another. In November 1977 my first child, a boy, was born. I was a newly qualified doctor of one year's experience. It became clear in the space of twelve weeks that all was not well and that he was failing to put on weight. Over the course of investigations he was found to have cystic fibrosis. Left untreated with antibiotics, the vast majority of children with cystic fibrosis have died by their fifth or sixth birthday. But if regular physiotherapy to clear the chest (typically six episodes of fifteen minutes a day) coupled with regular antibiotics are administered the mean survival of this group can be raised to sixteen years. My wife and I started to meet other families in a similar predicament and what we saw was that raising the survival rate from six years to sixteen years was not necessarily in everyone's interests. Most of the parents had become divorced. Many of the other children in the family appeared resentful of the attention and many of the children with cystic fibrosis themselves seemed angry at being brought to a level of consciousness where they were made aware of the fact that they were going to die at a young age.

We began to take the view that 'treatment' of this kind served no purpose. We tentatively explored the notion of allowing 'nature to take its course' but were quickly told that they as doctors they were the guardian's of the child's 'best interests'. They would, if necessary, resort to legal action to enforce treatment. We recognised their good intentions but their efforts were going to be devastating to both our child and ourselves. For all of us seemed to be facing pain and suffering without meaning and this course of action did not seem to be in anyone's 'best interests'. We both instinctively felt that a model of decision making that incorporated our own input was needed.

In 1977, the response we had received from the medical team was determined by a notion of 'best interests'. What is meant by the idea of 'best interests'. Does it mean best interests of the child, the parents or the whole family? "The state may be limited by the best interest criterion when dealing with children, but parents are not. The state's relation with the child is formal while the parental relation is intimate, having its own goals and

purposes. While the liberal canons insist on the incompetent one's best interest, parents are permitted to compromise the child's interest for ends related to these familial goals and purposes." (Schoeman, F. 1985. p45)

This absolute view suggests that there is an ethic imperative that some outside agency acts as the final arbiter of the child's best interest. Insufficiently confident of our own feelings in this situation we let the matter rest. When he unexpectedly died six months later whilst undergoing treatment on the hospital ward, along with our feelings of sadness and unfulfilled expectations, there was quite a feeling of release for him and for ourselves.

The management of this problem had two parts to it; making the diagnosis and instigating treatment. The first diagnostic stage was undertaken without reference to us. The investigations that led to a diagnosis needed a directive style of leadership by the doctors where they took complete control. It felt very reassuring and appropriate that they did so because for both the doctors and ourselves, purpose was the same; to find out what was wrong. When the diagnosis had been made, treatment was begun and continued without any reference to us. The moment that the nature of the problem became clear, particularly the consequences on both the everyday lives of our child and ourselves, then both my wife and I felt that we should have had some kind of input. It was not even a question of persuading the attending paediatricians to discontinue treatment, it was more a need to have some kind of framework in which the non medical aspects of the disease, the impact on the family unit, should be considered in the overall management. The 'expert' knowledge we had about our family should have formed part of the decision making process. The directive style of leadership, which we perceived as appropriate for the diagnostic stage, continued without pause or reflection into the treatment phase, when the purpose of action had changed. The commanding, prescribing behaviour of a more directive style in the doctors felt to us at odds with the participative/ appreciative style expected of this group with it's family coalition. We tried to discuss this and I sensed that the actions of the paediatricians arose out of three positions.

1. They knew that the child would not survive long and it was their duty to treat as best they could.
2. They belonged to a specialty, which had, over the years, made incremental progress towards cures of various diseases. We would be part of the long-term experiment that lead to a cure. The fact that in the process our lives would suffer accordingly was part of the tradition of progress. Some degree of 'sacrifice' (literally on the part of our child, and emotional on our part) was the price of progress.
3. They genuinely believed that he would be cured by the treatment.

Of course, today things might have been different. These events took place twenty years ago and a more contemporary view might respect shared decision-making so that "in the best interest of critically ill children, parents should be the primary decision makers in collaboration with health care professionals." (Rushton. C. 1990. p206; Hardwig J. 1990. p5).

Other doctors in the consultation room.

If the clinical consultation is re-framed for a moment and seen as a group, what effect does this have when one considers another doctor or student in the room? How might this influence the situation? First of all, I found that simply raising an awareness of this 'medical coalition' between doctors suggested that attention should be drawn to it. I began to change my practice to make sure that as each patient entered the consultation room, the doctors or students were introduced to them and that the *role* or purpose in being present is made clear to the patient. This meant emphasising that other doctors or medical students are there to learn but may well be able to offer additional advice. Very few patients seemed to object to this and usually responded by saying that they understood that it is necessary to learn. However, the balance between observing, learning, practising and participating is tricky and the presence of a 'learner' in clinic carries with it all kinds of implications. There is, it seems to me, a suggestion that patients are there to be *practised upon* both in outpatients and possibly by inference in the operating theatre. What is the evidence for this?

The standard National Health Service consent form has a section advising the patient that signing the consent form does not guarantee that a particular surgeon will undertake the operation. It may mean that surgery can performed by a trainee with no guarantee to the patient of training status, competence or level of supervision. It suggests that the system allows procedures to take place in less than ideal circumstances, with less than perfect results, in the interests of training. Patients, if you like, may be 'sacrificed' so that a novice may learn their craft.

Valerie relates an experience when an inexperienced trainee operated on her with significant consequences. The experience raises a number of issues. It particularly suggests that the medical organisation can convince patients that the system is safe but at the same time makes it difficult for them to question this. However, the main purpose in including this extract is to show the relationship between consultant and trainee in terms of practising skills upon patients in a way that may not be in the patient's interests.

Valerie describes how her brain cyst was aspirated by a trainee on the open ward. The entries in brackets are comments made by Valerie on reading the transcript.

"V: Because I wasn't sure that I was right and because I believed that my consultant who was supposed to be good would not let that man do it if he was not good enough.
R: So you had belief, an intrinsic belief in the system?
V: Yes, it was a young consultant. As far as I knew I was in the best neurology hospital in the country - if not Europe. This man surely would not be in his position if he were not pretty special. My consultant had spent about ten to fifteen minutes chatting to me, leaning against the wall near the desk, before lunch. During this chat he told me that this procedure was not a problem unless of course (he mimed) you pulled the fluid off the brain too quickly. In which case you might cause a thrombosis - a stroke - or similar. He departed with a friendly grin saying he would 'get one of his boys to do it.'

(I desperately hoped in advance that it would not be the one who came. (He had two registrars.) The man in question had personality problems that were openly discussed by the nurses, who said that he constantly told them he did not have enough confidence, this they did not believe since he behaved so arrogantly. He looked and dressed as though he might be a slick dealer in the 1980s stock exchange.

He had brought me the consent form for my operation on the night I arrived. He had not expected me to read it and was very impatient when I tried. It was impossible for me to read it with him fidgeting and I capitulated to the system since I knew there would be no alternative, but I asked him what would happen if the operation went wrong (neither my neurologist or surgeon had told me about the risks of brain surgery.) He simply grinned idiotically and said "We'll make it better". I gave up and he produced a fountain pen with red ink in it for me to sign - in the circumstances it looked like blood. He then tried to get an Indian - possibly Sikh - woman to sign and gave the same responses when she could not understand it. She was unhappy and refused until her husband came in later.

I have since decided that although my consultant was or is supposed to be very bright - the pathologist husband of the woman next to me had looked up his "form" - he was still in his thirties and he probably lacked experience both of casework and of leading his team. I know that registrars have to gain experience, but he was unaccompanied and I think in view of the state of my lungs the consultant should have taken particular care. Then I feel guilty for even thinking that.) (Comment added by Valerie on reading the text)

I've since formed the opinion that Ok, you know, he may be a brilliant technician and brilliant surgeon but he has not had enough experience of leading a team and he talked to me for twice as long in the morning, the consultant, as it took the guy to take the fluid out of my brain, he could have done it himself while he was talking to me. That sort of thing, you know, happens, you know. I suppose nobody's going to learn unless you're allowed to do things but....

R: But what stopped you? What, what actually stopped you?

V: I don't know, it was a complete nightmare because as soon as he'd done it and I'd realised he'd done it practically in a second or two and I thought, am I still sitting here because the consultant had told me in the morning that of course you can't draw fluids out of the brain quickly like that." (Appendix 3 Valerie)

Valerie points out that in the time it took the consultant to explain to her that someone else would come and aspirate the cyst in her brain, it would have been possible to have undertaken the procedure himself. Such a situation forces one to examine the way that the system allows room to be made for trainees to practise procedures.

Such practise can take a number of different forms. Animals are frequently 'sacrificed' in the interests of research, developing new surgical techniques and practising surgical skills. Surgeons practice upon deceased 'patients' in the post-mortem room and this takes place regularly in my own hospital. This idea of practising is ultimately extended to live patients. When a new technique is introduced, and this in recent years is most evident in heart surgery, there is a 'learning phase' during which the results may be poor until the surgeon has developed his or her skill. Such patients are seen as a sacrifice in the interests of advance and I have heard colleagues talk of a 'surgeon with a touch of the Prussian General' who has the stomach to make such sacrifices in the interests of advancing knowledge. So that to the medical establishment the idea that trainees practice on patients, and specialists make advances by practising on live patients, may not be so far removed from the notion of sacrificing animals in the pursuit of surgical education and improvement. Are there circumstances that test this notion of sacrifice so that it is then seen as inappropriate?

The moment another healthcare worker has to have surgery, particularly another doctor or a nurse, it is a widespread practice for the consultant to perform this surgery themselves and trainees are not involved at all. Certainly specialists don't seem to advance their expertise by practising upon other doctors or healthcare workers. This can be extended to the families of doctors and surgeons depending upon the importance of the

doctor concerned. A distant relative of a famous surgeon can expect the same treatment as a doctor and part of the game plan of such a patient in the outpatient consultation seems to let information about other medical members of the family become known. Sometimes the family practitioner will do this for them in the referral letter. There is an unspoken dialogue going on in which such patients are identified as not suitable for 'sacrifice'. Furthermore, it is interesting to note that trainees only 'practice' on National Health Service or public service patients and that they are not present in a private Independent Hospitals to 'practice' on private patients.

Of course I use the term 'sacrifice' here in a archetypal manner. What I am trying to convey by highlighting the different hierarchies of treatment and is that other *purposes* may be at play. It is suggesting that below a level of purpose that would accept that training is necessary is a level of purpose that includes reference to sacrifice. It is as though the ancient notions of more obvious sacrifice have become hidden by the surface of technical medicine.

Re-framing like this started to make me feel uncomfortable. This resulted in a shift of attention from the actions or strategy of everyday practice towards attention to purpose. This meant concentrating on the *purpose* underlying their presence and to try and make this as clear as possible. If patients were listed for surgery and it was likely to be undertaken by a trainee then this was pre-agreed with the patient. Otherwise I would note on the admission card that I alone would undertake the surgery (a manifestation of Torbert's logistical power). An attempt was made to match the appropriateness of the surgical task to the skill of the trainee. In this way it was made clear to the patient that they were not being practised upon. During the course of this thesis, all surgical lists by unsupervised trainees ceased and only those with a higher surgical degree were permitted to undertake surgery. I cannot necessarily be sure that this change in the department is connected with such re-framing but as a key member of the department I can claim a part in this. How do I know that fundamental assumptions have been disturbed? I recall the awkwardness I felt in beginning to appreciate that practice and sacrifice may not be so distant from one another when I considered the role trainees played in the organisation. I

take this sense of awkwardness, like embarrassment earlier, to be a simple validity claim that change had taken place.

As a researcher I notice how difficult it is to track the process from re-framing to actual change and furthermore, how difficult it is to convince others that this has taken place. Part of the reason might be that such change does not take place in isolation. These changes reflect a wider cultural and historical movement that includes challenge to the notion of professionalism to govern itself, to give a greater account of itself and to justify certain practices in public. As I write this, the hospital is introducing the concept of 'clinical governance' a disciplinary structure that monitors and questions and prohibits such practices. The idea then that surgeons can practice on patients in a manner that is unaccountable is part of a wider cultural shift in attitude. In such circumstances it becomes difficult to be sure just how much is generated by such re-framing as above and how much is part of this wider shift in attitude.

It would be an oversight to conclude without examining for a moment the connections made between the patient and those doctors other than myself in attendance. I began to notice that for much of the time the patient would largely ignore any other doctor in the room except if a female doctor was observing/attending and a female patient came in when I sensed a connection between them. For example, replies to my questions would be made, not to me, but directly to the other female doctor or medical student. If this started to happen, sometimes the other doctor or student would start to ask the patient questions themselves. Such a relationship between male doctors observing male patients or male doctors observing female patients seemed to be much less common although occasionally a male patient would start to form such a relationship with a female doctor. Is there evidence to support a different clinical relationship based on gender?

There is no literature specifically on the subject of relationships of this kind but it has been shown that female doctors spend more time with their patients than male doctors. It is about three minutes per patient in general practice and one minute per patient in hospital practice (Cypress BK. 1980). Most of this difference is time spent when a female

doctor sees a female patient. Male doctors it seems tend to spend equal time with both sexes. This may be so for many reasons. It may be that for some reason it takes longer for women to take or give a history than men. It may be that introductions take longer. Some work has suggested that there is a perceived preference on the part of women for a woman physician (Grant 1988. p115) There are many possibilities here. Consequently, I tried to inquire a little into the nature of the connection between a female doctor in attendance and a female patient. I noticed however that whenever I raised this as a process issue, and inquired what such interactions might mean, or why they had taken place, it usually resulted in a certain awkwardness or embarrassment. The other female doctor would apologise for "interfering" and remain conspicuously quiet for the rest of the time.

The place of gender as part of my medical discourse is seen in the following entries especially in the way I portray female voices in the diary entry following the meeting of the hospital inquiry group. My attention was drawn to this by the supervisory process, and it eventually led me to re-evaluate my position in the organisation as a white middle class professional male. This diary extract is taken from the first clinic following the first meeting of the Hospital Inquiry group. The inquiry group had finished by setting itself the task of looking for a small change, a small improvement to make in the running of the clinic.

DIARY

7th November 1990

Head and Neck malignancy clinic. Attendance: SELF, 'R' AND 'T', Consultants; 'H' Radiotherapy Consultant; 'Rd', Consultant in Palliative Care; 'S', Senior Registrar; 'G', Registrar; 'P', Registrar in Maxillofacial Surgery; 'C', 'H' (Part Time), 'K' and 'A', Senior House Officers; 'M', House Officer; 'D', Nurse from the ward.

This is the first clinic that has been held after our initial meeting. I am conscious of a number of things. 'H' our part time doctor with us only three days a week looks very

much as though she wants to opt out and is also clearly very uncomfortable. Actually she tells me some two to three weeks later when I mention this that in fact she is not well. She mentioned in the meeting that lack of seats was a problem and significantly contributing to the level of exhaustion we all experience. I get her a seat. It doesn't really help. I know that there are problems between her and the rest of the junior medical staff over the rota and time off over Christmas and I wonder if this is a factor. 'K', who is keen to please and anxious not to upset anyone, gets very involved in the discussion. This helps a lot. On one occasion she becomes a key member when one particularly frightened woman recognises her from a previous admission to the ward and immediately adopts her as an ally and friend. 'K' is very helpful in the discussion we have afterwards with the patient when discussing options and does an impressive job in comforting her. 'C', who was, I felt the most vocally critical of the clinic in the first meeting is away. I don't perceive any real change in the others.

This clinic was followed three weeks later by the hospital inquiry group. This is a further extract from the reflective diary made after these meetings.

DIARY

28th November 1990

2nd meeting of multidisciplinary group. Attendance: 'R' (Leaves after 30 minutes, 'Rd', SELF, Consultants; 'S', Senior Registrar; 'G', Registrar; 'C', 'H' (Part time), 'A', Senior House Officers; 'M' House Officer.

I start the meeting by showing the flip charts, which we produced at the last meeting. It's pretty negative stuff. 'R', who wasn't there at the first meeting, is, I think, a little hurt (perhaps that's too strong a word) and immediately engages largely with 'S' in a conversation to bring out some of the more positive and helpful sides to the clinic e.g. teaching. Pretty soon the meeting is lively and vocal but virtually all the conversation is between 'R', 'S' and 'Rd'. Much of it is directed by eye contact at me as apparently the chairman. I begin to feel uncomfortable. Firstly I don't feel responsible for the clinic, its construction and what goes on in it; in fact, rather the opposite. Part of the reason for

doing this research is to look at ways to change it in a constructive way. Secondly, I am not doing my job at all well as a facilitator within the group if my position as Chairman is being acknowledged by all implicitly. I decide to say something direct and mention feeling uncomfortable and immediately there is a change.

'S' says that he thought I was leading the discussion. I realise that to a new member I had failed to make my position and interest clear. The lively discussion between the above three continues with much gusto. It goes on for about ten to fifteen minutes and the others (all girls except me) are merely observers with little or no eye contact between the three in discussion and the rest. It is exactly like the head and neck oncology clinic. The senior medical staff talking, deciding, sparring etc. and the rest observing. I am in a dilemma. Do I mention this obvious analogy and threaten to inhibit 'R'? I think he has joined with some misgiving and perhaps out of a sense of friendship or whatever but now seems to be enjoying the whole process. The same thought I sense is true for 'S' and 'Rd', who, as a consultant in palliative care is perhaps the most at home with this sort of thing and is clearly happy to get involved straight away. I watch the watchers. I am puzzled because they don't seem discomforted particularly by all this, except possibly 'H'.

The women in the group are being marginalised. By failing to contribute or more accurately engage in the group discussion, it is failing as a group. Secondly, I don't like seeing talented and capable women being dominated by men (who are also talented and capable I should add) and finally I am anxious to empower them to help them realise that they are not only capable of but entitled to contribute. Later on I learn from them that they are stuck on the idea that they are not really permitted to contribute to discussions about treatment because of their insufficient knowledge and experience. I decide to comment on the fact that the women are being left out of the discussion. This certainly frees them up for a moment but after a minute or so the discussion between the men starts up again. It is not until 'R' gets up to leave, clearly wishing to stay because he continues to talk even as he closes the door to leave, that the discussion really becomes more generalised.

'C' makes a good observation. She accuses me of only putting negative comments on the flip chart and I choose to ignore positive comments. This tells me two things. Firstly that I am consciously looking for problems within the clinic so that at a later stage I can say to myself how I have improved all these things and the other is that by writing on the flip chart I can partly control, manoeuvre and manipulate the group. Of course she is absolutely right.

'H' leaves at about 4.40. The effect of people leaving on the group is interesting. Generally it is helpful. The group becomes smaller but a more subtle effect is that of the level of contribution made by those who anticipate that they will have to leave. 'R' who knows that he will only be attending for half the session and is comfortable in the group occupies a lot of airtime before he leaves. On the other hand 'H', I postulate, knows she will be leaving halfway though and wonders if it is worthwhile really "getting into it". A non-contributor leaves. Non contributors cause the rest to fantasise why they are silent (disapproval, disagreement etc.) and can in turn block us.

A general discussion follows. 'Rd' suggests introducing a clinical psychologist to map interpersonal interactions within a clinic but nobody seems too keen on this idea; perhaps the group is too young. I remind everyone that our stated aim for this meeting was to suggest a small change to the clinic and the way it is run to try and improve it. We agree to change the seating arrangements. The bulk of the seats will be placed around the edge of the room with three seats left for the main 'actors' in the drama, the three consultants. I personally express reservations because it seems to me that that it will only serve to increase the barrier between the consultants and the rest of the staff by having a 'stage and audience'. I have images of victim, firing squad and official observers. The others disagree. At last we agree to try this. I personally think that it will make things worse but let's try it.

When I read this now, I feel awkward and have to resist the temptation to alter it. To me, this embarrassment feels more like a validation of just how far my position and attitude has shifted since writing the diary five years ago. On a general level, the assumption I

make about what others think and feel without any effort to confirm these inferences is evident. On a more particular level, I feel awkward in reading about my desire to offer protection and empowerment to the "girls" in the department. I would not use the word "*girls*" if I were to write a diary today. As a researcher I ask myself what does this tell me about my perceived position in society? My espoused theory is one of protection and empowerment of the younger female members of the department but what is my theory in use here?

Through the use of this gender frame, I first begin to notice the gender discourse that is evident in hospital life. The use of the word '*girls*' when referring to female members of staff, doctors and nurses, seems to be widespread in hospitals and my casual use of the word would have been typical. Male members are more usually referred to as 'men' or 'doctors'. There is an implicit hierarchy between men and women within the use of such terms. At the very least there is one of age, young/old and possibly one of father/daughter, teacher/learner, protector/protected. It is a discourse of power as well as of gender. The wish to *"empower them to help them realise that they are not only capable of but entitled to contribute"* is not so much a wish to empower but a power statement about my own position as a male in the organisation. It is what Benokraitis and Feagin referred to as "condescending chivalry." (Benokraitis NV & Feagin JR. 1986)

The gender and power discourse evident in the use of language is reinforced by certain structural expressions of gender and power within the fabric of the organisation. Most surgeons are male, indeed the proportion of consultant surgeons who are women in the United Kingdom and the States is apparently less than it was thirty years ago, despite the increasing proportion of female medical graduates. (Lorber J. 1993. p66). Most of the senior medical staff are men and of 135 consultants at the Royal United Hospital, 14 are women. This disproportionately small number of women at senior level is made even more evident because at the junior level women outnumber the men. A doctor's dining room conveys this sense of male superiority. All men on the 'head' table, all women on the juniors table. Indeed the term 'mess' is one borrowed from the military vocabulary.

Furthermore, most nurses, physiotherapists, radiographers, blood technicians, receptionists, secretaries and others occupying similar supportive roles are women.

It seems fairly obvious that this imbalance in gender and power in organisations does not just apply to medicine but is an issue that is widespread. What is odd about this position in medicine is that men have somehow usurped the perceived 'caring', 'nuturing' role of women. Riska believes that the liberationist rationalism of the nineteenth century was in reality an opportunity for medicine to subvert other healthcare occupations, which by their nature were women dominated (Riska.1993. p2). The official history of the Royal College of Surgeons of England portrays part of the story. There was indifference towards midwifery as a specialty suitable for recognition until women were admitted to the college in 1876. Some women wished to take just the midwifery exams but this was disallowed. (Cope Z 1959) This and other similar disputes resulted in a new division of healthcare labour that placed men firmly upon the top of the hierarchy. This domination of men over women, by doctors over nursing, is even more complex because of internal gender generated divisions between nurses themselves.(Carpenter M. 1993. p97)

This suggests that my experience of progressing through medical school, progressing through the training grades and working as a consultant in a hospital for ten years in an organisation that is male dominated and male *structured* is likely to generate a level of expectation as a male. What are my assumptions as a male? This whole question can be further extended to include race and class. What then are my assumptions as a white, middle class male? Such a question cannot be addressed without considering the nature and use of power.

Power and Medical Power

I have been asked by the examiners to make a choice to develop one of the topics of 'groups', 'leadership' or power. I have chosen 'power' because the problems of power are widespread within organisations and embedded within epistemology and methodology. The exercise of power is a multi-dimensional concept that involves the "control and manipulation of knowledge and knowledge structures" (Cutting 1994 p20) so that as organisations take structure there are those who "are experts on the form, those who are novices, and those who are, or will be, the victims of another persons stock of knowledge." (Denzin 1983 p139) Furthermore these structures themselves are constructed by those who are in control of such knowledge, who determine what is truth, what is not truth and what validates either position. Power is also an issue in any relationship between persons and within groups; it is a force in the "interpersonal dominance actualized in human relationships through the manipulation, control, and often destruction (both physical and mental) of one human by another human." (ibid) In a sense 'power' would need to be discussed if I chose almost any other topic to develop for it is not only an important concept in the doctor/patient contract but universally.

I found it hard to know where to begin a discussion on power. My everyday experience suggests that power is applied to produce results; parents, teachers and managers do this. This stems from my experience as a child in a family, in schools and organisations such as hospitals and universities. I notice individuals accumulating power as a kind of organisational currency that determines worth or importance. People talk about 'getting more power', chairing more powerful committee meetings, occupying more powerful positions or being more powerful. I find myself caught up in this exercise and any change in the organisation includes an evaluation in these terms. Such an approach does not explain in adequate terms the relational nature of power; what happens when two powerful people disagree; what happens when groups become powerful, for in this situation power seems to reside within the relational structure of such groups rather within an individual. An example of this is the power of the medical establishment in society in general. Such power does not reside in one individual but as agency power in

the office and structures of the organisation. This suggests that a pluralist approach may be needed to adequately convey the way power enters our lives in ways that is not at first obvious. "Power is best approached through a view of more or less complex organised agents engaged in more or less complex organised games." (Clegg 1989 p20)

So in tackling this I have chosen a framework that acknowledges a pluralist analysis of power and moves from the general to the particular in the following fashion.

Some broad schools of thought on the subject of power.
Some selected philosophers to study.
My position in life and the organisation as a white, middle class male.

In following this structure I have tried to pay particular attention to implications of power in the doctor/ patient encounter. This approach also recognises that this is not a thesis on power and so trying to understand power in the clinical context, an approach that is practical, would, I hope, be sufficient and appropriate.

Some broad approaches or structures to the study of power

I have chosen four broad approaches to the study of power. They are those offered by Clegg, Marshall, Vince and Torbert. They are all pluralist in concept but emphasise different aspects of power. For example Clegg adopts an historical position and reading his work I am left with the impression that power is perceived in terms of control, distribution of resources, manipulation as the dominant description. Marshall puts forward a more optimistic picture of power drawing particular attention, as I see it, to notions of co-operation and personal power. Vince highlights the assumptions that white middle class professional men hold in organisations. Torbert adopts a developmental approach both in terms of linking different types of power to different stages of childhood and adolescent development in suggesting that different types of power may be appropriate depending upon the time-scale of the project involved.

Clegg's approach

Clegg identified two historical approaches to the concept of power, those derived from Hobbes and those derived from Machiavelli. "Hobbes sets out the terms of a debate around a conception of sovereignty and community, Machiavelli initiated a concern with strategy and organisation." The approach of Hobbes concerns itself with "what power is" whereas, Machiavelli and his successors interpret power in terms of what it "does." (Clegg 1989 p5) Historically, the view of Hobbes has, until recent times, attracted most attention with its emphasis on conflict and the theory surrounding it. Contemporary debates, particularly the work of Foucault, have revisited the approach of Machiavelli and questioned the assumption that power is necessarily an analysis of conflict. Power is somehow in the system or culture that we inhabit and controls us, principally through the use of language, in ways that may or may not be obviously in our interests.

Clegg identified a number of questions that any analysis of power needs to address. "Is power distributed plurally or held by an elite? Is power intentional or not intentional? Is power confined to decision making or is it evident in non-decision making? Is not making a decision an action or a non-action? Is power a capacity for action or the exercise of action?" (Clegg 1989 p37) These are important questions but the nature of them is all the same. They are questions that consider power in unitary terms, as a single phenomenon and approaching power in this way was, according to Clegg, part of the problem. Historically, questions like these have sustained an approach that persisted in thinking of "conceptions of power in unitary terms to which all issues of theorization must be resolved." (ibid)

Clegg offers an alternative construction of "three distinct but related conceptions of power" and configures them accordingly in terms not only of their internal relations but also their relations to each other. He goes on to suggest that "it is less important to adjudicate the debate by declaring in favour of this or that true concept of power, once and for all time." Instead he suggests exploring the language games for theorising power, making a note of the political myths, identifying the rules of this and "pinpointing a few

moves and strategies within them." Perhaps, he suggests that it "is these moves, these strategies, these passages constructed through the ensnaring funnel-web that prototypes of power may be seen?" In this way power consists in the "networking of relations, in the way in which moves in the game implicate others as allies or adversaries in one's interpretation of what the game is." The suggestion is that such networking or relations, such constructions, are themselves sources of power and that there is no escape from such an analysis. Perhaps, he argues, "we are as much condemned to interpretation as we are to strategies of power." (Clegg 1989 p38) This observation prompts me to ask what is the purpose behind my own attempt to interpret the nature of power. For example, is my attempt to analyse the networks and relationships of power that characterise my own life and organisation, an attempt as an overt conflict theorist to acquire power in a way that identifies allies and adversaries? Although I hope that this is not necessarily the case, I have developed sufficient circumspection to know that it is a question I cannot immediately answer.

How then does Clegg construct his vision of power? The three "distinct but related" concepts of power described in his framework for analysis are 'agency', 'power and resistance' and 'episodic power.'

Agency

Agency, is not a generic term for 'people.' It refers to the collective forms of decision making of the kind that takes place in organisations. The concept of agency is seen in the "purposeful goal orientated action" that characterises organisations. The purpose of all forms of agency is the "achievement of control produced by discipline." Consistency of action and thought, coherence of action and view and memory of self are all phenomenon that are "learned and accomplished". When this is achieved organisationally, it results in the "stabilization of power relations across an organizational field of action, and thus between many subjectivities, rather than simply within one embodied locus of subjectivities." (Clegg 1989 p188)

The mechanisms of such organisational control manifest themselves through the disciplinary practices of surveillance. Such 'disciplinary practice' not only normalises individuals but also other collective organised bodies through comparative data. Such surveillance, which is more than simply a question of direct control, may be personal, bureaucratic, performance, legal, ethical, persuasive, enabling or morally endorsing and represent "the extension of direct, personal supervisory control into notions of individual space which previously were private." (Clegg 1989 p191)

From my perspective in hospital, this surveillance can be seen in at least two ways. Firstly, in the way that I am normalised by disciplinary practices and secondly by the way that it 'entitles' one as a doctor to undertake surveillance of patients. The first is an example of constraint that the organisation imposes on me, makes me 'obedient', in return perhaps for the second, the assumed power to impose constraint on others, to make them 'obedient'. In the last few years there has been a considerable growth in the development of such surveillance centred on the acquisition of data. For example, every department is obliged to audit some aspect of the organisational process in a manner that adheres to a recognised audit methodology. This identifies actions of the organisation and individuals that departs from normal so that incorporated within the methodology is a mechanism that suggests action to restore normalcy. This includes audit of quantity and quality such as surgical throughput, surgical results and complaints. This is extended to include comparative data with departments in other hospitals with centralisation of such data by medical institutions such as the Royal College of Surgeons, institutional bastions of disciplinary power. Self surveillance may be important as well in maintaining a profile that is not made visible by the organisation's own surveillance procedures.

Such restrictive agency power to make me 'obedient' is offset by conferring on me the power to make others 'obedient'. As a doctor this is perceived as the medical surveillance of patients, which include not just medical but personal questions as well. This surveillance underpins the routine questions that form part of the routine clinical examination. I have a sense (which may be an assumed privilege I have as a white male doctor) that I am entitled to ask almost any question in the interests of supposedly

understanding the problem. The way I have been taught to ask such questions also suggests that I have access to a repository of normative data. For example, take the question that forms part of the routine history taken from a psychiatric patient; How often do you have sex each week? This question, which I was taught to ask *every* psychiatric patient regardless of the problem, can be seen as an invasion of privacy. We were taught to ask this and other awkward questions in a certain way; How often do you have sex each week, never or 20 times? The espoused purpose of asking a question in this way was to create the environment for an 'honest' answer. The theory in action may have been to suggest that as a doctor you possess a body of data encompassing the complete range of possibilities in the community and a clear conception of what constitutes the 'normal' number of times.

The existence of agency suggests a relationship where empowerment was dependent upon being 'obedient'. Clegg argued that agency directed delegated routines with discretion in a way that could inhibit or empower. He drew attention to the relationship between power and discretion, to what he called the "central paradox of power". If the power of an agency is increased in principle by that agency delegating authority, then the delegation of authority can only proceed by rules. These rules necessarily "entail discretion and discretion potentially empowers delegates." From this process arises the "tacit and taken for granted basis of organizationally negotiated order" that resulted in what Foucault referred to as "interiorized normalizing gaze of professional self-regulation". (Clegg 1989 p200-201)

Such a model of agency with many other agencies such as a hospital needs to consider the relationship one agency might have with another agency; what Clegg called a "disciplining of the discretion of other agencies." (ibid) I perceive hospital life as a myriad of mostly professional agencies. These include not only the medical agencies of the Royal Colleges, the General Medical Council and the Medical Defence Societies, the General Nursing Council but also the many organisations that represent operating department assistants, physiotherapists, pharmacists, audiologists and other medical personnel. Furthermore, there are those in essentially non-medical tasks such as cleaners

and porters, who can exert agency as well if they chose not to clean the ward or take patients to theatre. What are patients to make of the many different agencies they experience in hospital competing for their attention, from the nurses, to the various doctors, to the porters, to the cleaners? What is also noticeable is the lack of agency that represent the patient, only the Community Health Council as far as I can see, who have no visible representation in the hospital. This contrasts to the many that represent the interests of the professions that work within the hospital. Over all of this the hospital management is attempting to generate strategic agency through the "disciplined discretion of the agency of empowered authorities, to enable creativity which is embued with positivity yet still constrained by discipline." (ibid)

I sense that such professional agencies strive to gain 'improved' positions with respect to each other. Evidence for this may be found in the following observations. I have noticed in the last twenty years of medical practice how pharmacies have gained control of drug prescribing so that at the present moment I can only offer patients a limited choice of drugs from a formulary drawn up by pharmacy. This is in contrast to no restrictions at all when I first qualified. The opening paragraph of the introduction to Project 2000, the new vision for nursing in the next millennium contains the statement, "the nurse is not the hand maiden of the doctor" and that the nurse is the "advocate of the patient". I notice that the sign at the top of the bed has the patient's name at the top, the consultant's on the bottom and the nurses in between. I am left wondering if there is any significance in this order.

Valerie touches a little on this when as she notices the complex agencies that pervade ward life. Although this extracts includes other observations, for example the way access to certain groups is restricted, the general tone of the passage is noticing the existence of various interested groups and the pecking orders that exist therein that may restrict access. From her observations patients find it easier to gain access to the cleaner than the doctor, which may not be surprising, but she detects barriers that help to maintain this. She notices the uneasy relationship that exists between nurses and doctors.

V: And the other part of it I think is the, the awe in which the medical profession is still held by people generally, most of all by patients, prevents many people from feeling that they can address issues about their treatment with their doctors; indeed they rarely have the information to do so. The language of the medical profession is very technical and specialised, whereas the concerns of patients are usually voiced very much in terms of their feelings, intuition and fear of consequences. In addition fear of the unknown plays a large part in a patient's comfort and it is rare for this to be dealt with in a supportive way by staff without underestimating a patient's ability to understand what is going on.

Patient's fears or enquiries are likely to be addressed to the staff, who are readily accessible to them, the less qualified grades of nursing staff. Although these nurses are often most sympathetic to patients, they too have little or no access to doctors and in passing messages up the chain of responsibilities they can get distorted and delayed. These worries are often not passed on to doctors in a way that will produce the required information. The 'named nurses' system of allocating specific nurses to patients throughout a stay in hospital depends greatly on the ability of the nurse and can be frustrating for patients since to some degree it blocks access to someone who may be more sympathetic; but most of all in the several stays in three different hospitals I have experienced recently this system is very unpopular with nurses, who simply don't operate it.

Although much has been done to make hospitals more friendly places, including breaking down what seemed fearsome hierarchies of anonymous staff, according to all the patients I have spoken to, it doesn't help if they are left not knowing where they are. Not wearing uniforms and white coats and nurses being apparently more on one level and known by their Christian names, not having matron and so on does not help if they don't know where they are in relation to staff. They need to know who to speak to if they want a real difference and who is accountable for their daily welfare. They need to know that even more when they are really ill because they have no choice but to put themselves in the hands of a system which they feel will be watching out for them and have its own checks

and balances. They need to know who can begin to make decision making, at least in part, accessible to them in a real sense.
(Appendix 3, Valerie)

Such considerations lead me to consider my position in the system, to what extent I am subject to medical agency, particularly in relation to this work. Part of the ethical position of this thesis is to contemplate a method of practice that attempts to make transparent to the patient aspects of the conventional agency of medicine. In this respect I am applying an element of discretion to my practice, that may or may not depart from the 'normalising gaze of professional self-regulation'. This may be laudable but what is the disciplinary process monitoring my part in all of this? My first response is to suggest that it might be my role as a researcher but this in turn prompts the question What are the agencies disciplining my role as researcher? I cannot help but notice that I have adopted a research agency, a school of management, that is outside the conventional agency of medicine and that this has been both fruitful and problematic. It has forced me to adopt practices of validity, in particular the relationship between data and inference, which brings to my attention the many assumptions I have made as a doctor. Although this may appear to me to have generated insights, the difference between these two agencies and the approaches offered by them may not in reality be particularly great. What if a patient where to enter the system with an approach to agency that is *radically* different from my own. For example, their system of medical belief may be founded on an entirely different authority from the conventional medical one. For example, David explains how he derived great comfort from faith healing.

So I went down to see this chap and uhh I, I had what he terms as 'healing' off him ***(1)*** *and felt considerably better* ***(2)*** *umm. At that time the* ***(2)*** *tumour hadn't manifested itself again, it was after radiotherapy but before* ***(1)*** *umm I got it in the neck and the* ***(1)*** *just in front of my ear there* ***(2)****. But I had got great problem with my left eye. The vision was down to* ***(1)*** *no more than 5% I reckon at that time. It was blood shot all the time and it was acutely painful, very, very dry, uhh, extremely light sensitive and after one visit to*

this bloke, it was all right again. Slightly blood shot but visions ***(1)*** *I'd say 95% again and I thought, that's fairly odd, (laughter,)*

R: *Mmm*

D: *Very odd in fact.* ***(2)*** *From there, I took a lot of time off work, had 3 months work out actually and I started to read all the great Eastern religions again, brought books all over the place and I started to have a look at spiritualism. Umm and it was fascinatingly similar to a lot of the Eastern religions* ***(4)****. From the reading of the books, I eventually* ***(2)*** *put a little bit of credence in what was uhh being said and I tried to see this faith healer that I had initially seen down in Wales again, it's a long way, he's an exceptionally busy man, people come from all over the world to see him and uhh it was getting more and more difficult to see the bloke so eventually I went locally to the spiritualist church and umm they have been giving me healing down there on a* ***(2)*** *weekly basis for about* ***(1)*** *10 weeks now* ***(1)*** *during which time I have improved enormously. You, you can probably see the lump in the side of my neck, I don't think that's huhh, since you last saw me I don't think you'd see a great difference in that.*

And later he suggests that I did not take this seriously enough

D: *No. No, not at all. I think* ***(3)*** *there was just one, one, one element when I, I started to tell you about going down to see this bloke George in Wales*

R: *Yes, I know, I remember that.*

D: *"Don't Dave, don't tell me". (Laughter.)*

R: *Did I?*

D: *Yeah, yeah. (Laughter). And I thought well, come on Richard that's a bit closed minded. (Laughter).*

R: *Thank you. I think the trouble is, umm, I, I, I, I will try to be more open about these things. It's very difficult. What, what ends up umm is people start asking advise about whether or not they think*

D: *Yeah.*

R: *they should go but the trouble is, I have no experience at all.*

D: *No.*

R: *I don't, I don't know anything worthwhile about the set up*

D: *Mmm*

R: *and I* ***(1)*** *I am careful to only claim any kind of experience or knowledge or expertise in rather a narrow area but I am aware that there are, there's much more*

D: *Mmm.*

R: *to the whole business of disease, medicine and life with the narrow perspectives that, the Western tradition probably gives us*

D: *Mmm*

R: *but I have to be very careful about claiming to be an expert.*

(Appendix 1. David)

In a sense my claim to be radical, to view the practice of medicine from a truly radical perspective is a sham. I would more seriously challenge medical agency if I had adopted a perspective centred on a different system such as the traditional African system. I have not which suggests that I remain 'obedient' at heart to conventional medical agency. However, I might argue that part of my position is to mount a certain resistance to an established position and such resistance, I would argue, may generate understandings.

Power and resistance

The second of Cleggs 'circuits of power' is the concept of power and resistance. In this respect he emphasises the relational quality of power and suggests that people " 'possess' power only in so far as they are relationally constituted as doing so." Power will rarely, if ever, occur without resistance from some quarter. This may either "consolidate itself as a new power ('organisational outflanking') and thus constitute a new fixity in the representation of power, or it may be resistance to the exercise of power which leaves unquestioned the fixity of the terms in which that power is exercised." (Clegg 1989 p207-211) This implies that there is always a dialectic to power, that any individuals position to

marshall influence will be, to a greater or lesser extent, diminished by another agency's power. According to this approach, as doctors adopt positions of power, they are likely to observe that patients will resist any expression of power to a greater or lesser extent.

In the medical context, attempts by patients to do this may be hampered by the fact that the language used to mount arguments by both patients and doctors may be different. The former may use everyday descriptions and the latter biomedical descriptions. One way for each to resist the power of the other is to fail to play the game and "try to resist the meaning in which one is being implicated in the other's moves." (ibid) An alternative approach is to learn the language of biomedical descriptions well and engage with doctors using their own jargon. I noticed, as Valerie gave her story of her illness from childhood to adulthood, just how rich in biomedical terms her language was, which suggests a strategy to overcome the problem.

R: Thank's Val. There are lots of questions I want to ask you but the one of the things that I noticed, was when you described it all that you use a lot of very conventional medical terms and a lot of the medical language. I mean it's a very sophisticated description and I would think from a medical point of view, you're extremely well informed. Is that how you view it all? Is that how you construct it in your mind?

V: It's the way the doctors tell me.

R: Does that, does that fit in how you'd like to see it or have you just found?...

V: Yes in a sense that I want to understand the doctor's language so that there is less of a divide between us..... I don't think one can underestimate the umm knowledge that anybody with a chronic illness gets of their illness and they certainly have a very, very strong idea of what is going to be good for me and what isn't and it, it quite often is right.
(Appendix 3, Valerie)

She went on to tell of an occasion when this knowledge had allowed her to argue in favour of one treatment against the advice being given to her. This appears to have empowered her to successfully resist the advice being offered to her.

Patients who arrive with a special understanding of their problem gained from medical textbooks or the internet, seem to generate more questions and consequently take much more time in the clinic. This would not really be very surprising, but as a researcher I started to pay attention to the way in which this happens. Familiarisation with biomedical language seems to enable patients to mount more effective resistance to my propositions, which in turn obliges me to shore up any arguments I have made with more information. In other words, resistance generates knowledge, an idea put forward by Foucault and which I discuss in more detail later. I also noticed that if I departed completely from biomedical language and use everyday descriptions instead, this would also generate more questions in the same way. My evidence for this was that in both these situations the clinic consultation time will be lengthened, a validity issue alluded to earlier in the thesis. What both these points suggests is that language may be used to limit opportunities for questions or to mount resistance to action. Consequently one of the difficulties associated with a strategy that is designed to empower patients by addressing the problem of language as a barrier to communication, is a clinic that over-runs. In my discussion with Patrick, we considered for a moment the problem of time and explanation in the clinic.

P: The, the second one is, is that uh uh the uhh consultation time that uhh the patient has, the opportunity to, to explore with doctor his full (1) medical condition.
R: Mmm.
P: Uhh that's umm that's very limited and I went away often I accepted it
R: Mmm.
P: and oth', other patients accept it because you, you as a doctor uhh in a, a year for example will see what, a hundred and fifty different patient? Perhaps even more and maybe less that's very uhh conservative but you have to share your time with
R: You may be surprised if I tell you it's more like three or four thousand.

P: Well you have to share your, your three hundred and sixty five days amongst those three or four thousand patients

R: Mmm.

P: uhh many of uhh of whom will have very serious illnesses because of the nature of your the work you're in. Uhh you also have a home life uhh therefore the umm the thinking time that you can give to your patients uhh and the interchange that you can have with your patients is extremely limited. The patient however, has all the time in the world. Not only that, he is traumatised to the point where he excludes all other thought and his thoughts centre on his problem and they roll around the brain endlessly. I know, I've been through it.

R: Right, well I mean, sorry, sorry to interrupt but what I was suggesting to you was that perhaps that is, that is the way the organisation is set up to prevent too great an interchange in discussion with quite difficult emotional issues which might include (1) cancer

P: Yes, that's right.

R: I mean that's certainly emotionally it's not intellectually the xxx thing to do but if your whole day is, is uh like that it can become exhausting and I, I just wondered if you had a sense that the way things are set up is to prevent too deep the discussion.

P: No, no, I, I think I, I, I have to say that of all of my doctors that they, they applied their time and their thoughts in the best way possible to help me.

R: Right.

P: I always felt simply that the number of patients you see, which is far more than I'd realised actually, is so great that your time of necessity has to be shared.

R: But I just, I didn't want to give you a sense of not being umm of being less important because you're part of the greater number

P: No, no.

R: But just the reality of it is

P Oh yes I understand that, no, I, I have no, no gripes about this. I think, we have how many doctors to the population? One in, I have no idea but one in a thousand is it? I'm not sure.) Appendix 2, Patrick)

What Patrick appears to be suggesting is that underpinning this notion of resistance and knowledge is an unwritten agreement about how much time can be spent with a doctor. For on the one hand his mind was full of thoughts and questions he did not ask but he went away broadly satisfied with the system. The doctor is prepared to give a patient all the time he or she needs. The patient is prepared not to ask for it. Such a position suggests that something is present in the process that discourages too many questions; resists desire for further knowledge. The maintenance of this contract may depend on subtle agreements that underpin this game. What happens when the rules are disregarded? In the gossip that exists between doctors, I notice widespread irritation with any patient who arrives with numerous articles on a particular medical problem and who proceeds to ask large numbers of questions.

There are two particular situations when the rules of the game may be disregarded. These are when the patient is contemplating a serious illness and when confidence in the doctor has been lost. In both these situations, it seems to me, the patient is not surprisingly inclined to take much more control, to take power, and overcome the resistance that discourages too many questions, or independent action on the part of the patient.

David, faced with a life threatening illness, was offered a second opinion and went to arguably the most prestigious head and neck cancer unit in the country. He was seen in the clinic by a well-known surgeon who strongly and uncompromisingly recommended radical surgical treatment. I asked David how he would have coped if that had been his only experience of treatment.

R: *What, how do you think you'd have coped if you'd met a surgeon who hadn't discussed with you the option of doing nothing?* ***(1)*** *Perhaps 'nothing' is the wrong word, of treating it conservatively or with alternative, none traditional* ***(1)*** *medical methods?*
D: *(Intake of breath.) Hooh crickey. That is a difficult one.*
R: *Could you have been sucked into the system do you think and, and not allowed your own choices or do you think you would have, you'd have, you'd*

have blocked that?

D: *Yes I would, without a doubt. I think uhh* ***(2)*** *if, if, if you, you look at structured Western civilisation there are all sorts of organisations who would dearly love to run your life for your and (Laughter)*

R: *Right.*

D: *and try to on regular basis and, and I'm cognoscente of the fact that you, you could be aware of it all the time, uhh, so no I, I wouldn't be forced down any particular route I don't think.*

(Appendix 1, David)

Given the circumstances of his problem, getting the 'right' answer was important. He seemed to indicate that he would be able to resist this medical agency with considerable certainty. Patrick recounts an occasion when he lost confidence in his doctor and took a decision to have more control on his treatment.

P. Huh, now you can understand, I think, that umm at this moment if we freeze this moment in time uh there was I worrying about a cyst, being reassured by all of my doctors that I had no umm cause to be alarmed about it in any way and suddenly (.) uhh it is cancerous and I'm right. Umm, the uh, the confidence in my doctors at that point in time dropped quite uhh considerably. And that's not to say that I wasn't respectful of my doctors and what they'd done for me uhh but I did feel at that moment. I remember saying to myself " be careful here; you're going to have to protect yourself in this situation and be very much involved in the decision making." I think that's a natural reaction for any patient to make.

(Being "right" boosted my sense of willingness to take an independent stance on decision making. That is to say, it gave me a private inner confidence as distinct from a "confrontational" confidence. Note added by P when reading text)

R: You mean in terms of further treatment and what you've decided to do.

His sense that the system was error free was shaken and as a result he took more control. The manner in which he portrayed this is interesting. Rather than overtly resisting any recommendations made to him he talked about a "private inner confidence" suggesting that disguised beneath an espoused theory of diplomacy, there might be a theory in use of resistance.
I do not see such action by David and Patrick as just exercising resistance to an episode of power but of exhibiting behaviour that the organisation would consider disobedient.

Episodic power

Clegg's third 'circuit of power' was episodic power. Episodic power "may be conceived as occurring within a reasonably well delimited framework in which there are systematic relationships between agencies and events." In other words something has to be seen to have been done in order for episodic power to have been exercised. This contrasts with the "dispositional" concept of power, that 'structures' agency and which is linked to the notion of a capacity to exercise power whether or not this is exercised. Clegg maintained that episodic power is "grounded in resource control"; there are some resources that can be activated in any struggle for power. Such resources are "deployed not promiscuously but with some target in view." The exercise of episodic power is a balance between achieving target and restricting the access of others to resources. (Clegg 1989 p212-217)
Such a sovereign conception of power, linked as it were to action, feels more familiar as a conception of power in a surgical discipline linked also to action.

What are the resources to be deployed? Obviously, these include resources controlled by the doctor. These include not only access to treatment, but access to information or expertise. General practitioners act as the "gatekeeper" to specialist opinions, and specialists act as gatekeepers to specialist knowledge and expertise such as surgery. It is also necessary to consider resources at the disposal of patients, which include paying for treatment. Resources are not always financial and I am conscious of the satisfaction to be had when treatments are successful and this is acknowledged by patients.

Clegg concludes his complex picture of power by indicating that power is represented in a number of different ways. It is "present as each specified modality of episodic, dispositional and facilitative power." It is also present in the "overall flow of action through the circuits of power and the relational articulation which will constitute the calibration of this flow." (Clegg 1989 p213) His metaphor of 'circuits' conjures up an image of electricity flowing from place to place, giving of fields of force depending upon its configuration at various points like magnetic coils and causing action at others like a light bulb glowing. Even the notion of resistance has its parallel in ohms's law. In this respect it is an explanation conceptualised in any everyday phenomenon but as a positivist such an idea makes me feel comfortable and suspicious.

Marshall's approach

Marshall draws attention to four assumptions that underpin many current models of power. They are that "power is competitive, a matter of individual ownership, motivated towards control and expressed through doing." She unpicks these assumptions to put forward an alternative vision which is "co-operative, based on joint ownership, directed towards influence and expressed in individuals' quality of being." (Marshall 1984) Marshall's four dimensional map describes power in terms of "over others", "structural factors", "through and with others" and "personal power".

Over others (1)

Coercion; reward; ability to access organisational rewards (and punishment) for others; formal/positional/legitimate; expert; referent/charismatic.

Structural factors (2)

Centrality to organisational tasks; handling uncertainty and risk; relative number; visibility; power through difference/new perspective.

Through/with others (3)

Informal networks; politics; coaching/mentor relationships; being attentive to wider community issues.

Personal power (4)

Competence; wholeness; self-esteem; autonomy; definitional sensitivity and capability; stamina/resilience; change and regeneration.

I see this description as a dialectical analysis of power. Although all of these are conceived as different kinds of power, the first two seem to highlight the 'conflict' nature of power and the second two highlight the 'nuturing' quality of power. This competition/ nurturing dialectic seems to me to ask questions about purpose underlying power that simultaneously encouraging diversity (through competition) and stability (through nurturing) as potentially key elements of a productive social reality. It suggests that the balance between all these elements is important in maintaining a system that is apparently functional. I can only resolve this in my mind by drawing parallels with the elements that ensure successful biological evolution; diversity in the midst of stability to ensure survival. I would like to hold this metaphor for a moment whilst at the same time describing this model in more detail.

The first dimension of the model, power over others, "relies heavily on traditional notions of power as a personal resource deployed to control the environment" but draws attention to the power whereby an individual can gain "access to organizational rewards (or punishments) for others." (Marshall 1984 p108-109) Such a view of power sees power as a resource to "control the environment" and is essentially developed from French and Raven's model. (French and Raven 1959). This first dimensional model is essentially episodic in nature and overlooks the "relational nature of the processes involved" and in doing so "encourages spurious notions of personal independence." (Marshall 1984 p109) This model is particularly well reflected in the merit award system that recognises personal achievement of consultants within the medical system. Each year I am asked to submit a record of personal achievement, which is evaluated by a selected group of doctors from within the hospital. Two or three consultants are given merit awards. I cannot help but see this in biological terms as equivalent to 'survival of the fittest'.

The second dimension, 'structural factors, acknowledges the "need and room for risk-taking as well as for risk-reduction" in any organisation. Innovation and difference allow an individual to become visible and if handled adroitly results in the "accumulation of personal credit." (ibid) Such an approach is seen to be very context dependent. It is a recognition that within the structure of the organisation that the generation of difference is a necessity for 'progress' for without difference, selection of suitable strategy would be impossible. Again such a model has echoes of evolution in that change and hence adaptation is not possible without diversity.

The third dimension develops a theme of co-operation by "creating power through relationships". These include "membership of informal networks, forming liasons to influence particular organizational issues, coaching relationships, social support, empathetic relationships." (ibid) This idea of power, shared by Srivastra, is dependant upon appreciating the *validity of others' experiences* and perceptions, to offer a greater capacity for power. (Srivastra & Barrett 1986 p321) Such relationships originate in a "wider attunement to the interests of the pair, group or community." Such power may be "fragile and unstable" so that "in crisis it is likely to revert to competition." (Marshall 1984 p109-110) This third dimension power is at least partly if not wholly dependent upon collectively agreed goals so that the resilience of this may be dependent, one might presume, upon the manner upon which these collectively goals have been agreed. This is likely to have been expressed through language. It has its biological equivalent in mutual nuturing, the collective desire to ensure survival of your gene pool, your particular interests as long as they are allied to the interests of the group. Srivastra suggested this when he talked about an organisation that is "an open ended evolving system" which a fundamental belief in "the open, evolutionary process of organizing, a sense that the organization is not a closed determined structure but is in a perpetual state of becoming." (Srivastra & Barrett 1986 p319)

Personal power is seen as "the sense of personal self-worth, an individual valuing and having access to all their characteristics through an aware, but not necessarily easily pleased self-tolerance." (Marshall 1984 p110) It is a sophisticated concept of self-esteem

"grounded in self-validation rather than ease in public relationships" the more usual definition of confidence. Such personal power is the means by which productive co-operative networks are developed and maintained because of the attention paid to the way "situations and characteristics are being defined and valued by others." An important element of personal power is seen in identifying characteristics that "threaten our integrity".(ibid)

Such an analysis suggests that the relational characteristics are important. How does the individual whose power principally resides in informal networking, coaching and attention to wider issues respond in the midst of an organisation emphasising the value of competition and visibility. The biological metaphor makes sense to me because it suggests that all types of power are needed to generate a system that is healthy provided these competing forms of power are balanced. At the same time I am aware that such a position might serve to justify the continuation of competitive, opportunistic 'leader of the pack' behaviour. Such behaviour is considered characteristic of many white middle class males and whether this is seen as a positive quality might depend upon perspective.

Vince

Vince identified three related perspectives on power that "constitute a general picture of power in organisations: discursive power, disciplinary power and episodes of power." Discourse in this sense is created "in the interaction between various phenomena: the social and cultural factors that determine the construction of meaning, the factors that constitute institutional knowledge, and the various systems within which behaviour is defined." (Vince 1996 p134) Language and knowledge of all kinds are viewed as instruments of power that impose form and order for the purpose of control.(Morgan 1983 p389) By drawing upon the work of Fraser he constructs a picture of the way that discursive power operates in day to day life. These comprise;

1. The officially recognised idioms (i.e. ways of talking about needs, rights and interests)
2. The vocabularies available (e.g. feminist, therapeutic, religious etc)

3. The paradigms of articulation that are accepted as authoritative
4. The narrative conventions available for constructing the individual and collective stories that constitute people's identities.
5. The modes of subjectification: or the ways in which various discourses position the people to whom they are addressed as for example, 'normal' or 'deviant'.
(Vince 1996 p134-135)

These elements of discursive power are seen as an expression of the "relationship between language (in a very broad sense) and power." (ibid) Habermas drew attention to four naively accepted assumptions about the nature of speech but which are made the subject of argument in discourse analysis. These are, first, "that what is stated is *true;* secondly, that the utterance is *comprehensible;* thirdly, that the speaker is *sincere*; and finally, that it is *right* for the speaker to be performing the speech act." Discourse analysis claims to explore these assumptions by examining and testing such claims through rational assessment. Habermas argued that "inherent in all speech is an 'ideal speech act' from which the sort of 'ideal speech situation' required for a rational true consensus can be derived". In a truly democratic form of discussion ideas flow "uncoerced" and participants are free from any form of domination, manipulation or control." He agrees that whilst this may never be achievable in practice, the very act of participating in discourse "carries with it the supposition that a genuine agreement is possible." Without this supposition the "very meaning of speech would be called into question." (Carr & Kemmis 1983 p132-140)

The circumstances that would generate truly democratic discussion are dependent upon "equality of chances to assume speech roles. If this were to happen, all participants would have the same chance to initiate or to perpetuate the discourse, to put forward, to call into question, and to give reasons for and against statements, explanations, interpretations, justifications and the same chance to express attitudes, feelings, intentions and the like." Truth , therefore, cannot be analyzed independently of 'freedom' and 'justice'. (ibid)

Speech and text then brings to life the networks of relationships and power that inhabit our world in terms of parental, developmental, medical etc agencies that determine our choices and behaviour. Inherent in this analysis can be found the "rules for reproving those who fail to adhere to it." (Banister, Burman, et al. 1994 p100) In this way power in all its forms and language are inextricably bound together. Vince links this idea to episodic and disciplinary power to ask pertinent questions about the assumptions that white middle class men make about their destiny and offers a pluralist view drawing attention to such assumptions.

"one of the things that white, middle class men are taught is to believe that we are right....led to believe that the world will fall apart unless we hold ourselves together.....we have not learnt that we do not have to be right...we have the right to control...defined authority in our own individual terms...ignoring a wider set of values....education encourages us to recreate the world in our own image...see life as the exercise of power, not as learning how to exercise power."
(Vince 1996 p140)

Clegg makes the same observation when he notices that "contingency reigns, albeit with a hegemonic personal cast" for past sociological observations have noticed that "certain male identities which are constituted in socially and economically privileged contexts will be routinely more strategically contingent for organizational decision-making, access and success in hierarchically arranged careers." (Clegg 1989 p198) This hegemony encourages us to "be competitive, rational and emotionless" to increase the probability of being able to get what we want from the world. Because these "value systems underlie organisation" such actions are given greater legitimacy, which means in turn greater opportunity. Such power gives "greater potential to act in a world defined by us" but also leaves us with the capacity to "be defensive about what we know" and chose not to act about it if we wish. This can be seen as a form of oppression as well as power, underpinned by an understanding of whose interest are served by any particular action or inaction. The value system that justifies action is that of white middle class values, in which others may participate if they accept such values. (Vince 1996 p141-143)

Can it be construed as an exercise of power if this is unintentional? Wrong would argue that such an *unintentional* exercise of power is not an example of power (Wrong 1979) but others, women and disenfranchised races perhaps would regard this as a naïve approach. The issue here is the context, the structural power that determines context and such context is a fundamental social reality as far as these groups are concerned. (Clegg 1989 p147) One could also argue that not only failing to recognise the presence of power based on the existence of a white middle class structure as an instance of power but also a *denial* of power's presence is also an instance of power. So what does Vince suggests? Like Marshall, his analysis suggests that a shift towards accepting responsibility *with* others and "finding ways of integrating the rational, emotional and political aspects of ourselves" would allow us to challenge such assumptions in a way that might serve to unshackle middle class white men as well as others. (Vince 1996 p144-145)

Valerie comments on the cultural, racial and gender differences that structure power relations in a hospital. This extract draws attention to the way certain doctors move and behave within an organisation, which suggests some ownership of the environment. The way a doctor can move noisily through the ward at night, which suggests that keeping a patient awake in this way does not matter. This contrasts with the attitude and demeanour of an Indian SHO, and the South American doctor/patient who seem to be offering a different approach. Whilst this account only represents one individual's experience with only four other doctors, I recognise my own unconscious actions in the attitude of the white middle class doctor in a way that generates some embarrassment, a test of validity I have alluded to previously. The extract is rather long, but I perceive this as necessary. The extracts in brackets are comments that Valerie made on reading the transcript.

V: I said this to Dr X. He had a really, really lovely Indian SHO who you probably know, who used to come into the ward very softly. I noticed by the way that all the staff always called him by his christian name not his surname which they didn't do with most doctors but he would sit on you know, sit on the bed, he would smile at you. If he came into the ward and caught your eye, he'd smile and say 'hello, good morning' or

something. All the other doctors, especially the young ones, they're terrified. They've got steel on the heels of their shoes or at least they've mostly got hard shoes. They come across a ward, clack, clack, clack, all the way over. They ignore everybody's eyes. They never meet an eye and they go to the bench and thing, whatever and write it down and then they go and see their patient and it's a kind of total funnel tunnel. It's impersonal and all the rest and you can't, I mean, it, it's been like that for donkeys years and I'm sure it's it's partly in the beginning for doctors a kind of mixture of fear and apprehension and all quite human things as well but it's also to do with esteem and arrogance and the different position in the hierarchy between the nurses and doctors. I don't think it should be perpetuated you know when they come in. I think it should be dealt with and I think all doctors should wear shoes that do not make a terrific noise when they walk across the wards, especially at night.

R: What, what does that tell you about the hierarchy for the position of patients in the ward then?

V: Oh well patients are there to be seen when the doctor's ready and only then.

R: You said 'doctors' Are doctors on top and then nurses? Where do the patients fit into all of this? Underneath, in the middle, on top?

V: Well I mean, none of them would be there if it weren't for patients but I don't think they remember that (Laughter.) I don't know where they fit. They're there. I suppose they are. I mean they have to be underneath, but it's not a, it's not the same logical thing, as nurses and doctors are all employed for patients.

R: I interrupted your train of thought on this. You were talking about doctors going through the ward making noise. That's what prompted me to ask a question. What is walking through a ward noisily at night saying about the environment.

V: I don't think, I don't think they think that consciously. I don't think uhh, I think there probably is a lot of apprehension in young doctors first going onto the wards. It must be pretty scary and I also know that quite a lot of you know, the way I mean, if you, you are experiencing seeing terrific pain and suffering or whatever, they would need to protect themselves and build up their own way of coping with it.

R: Yes

V: and I'm not talking about myself at the moment, and they see it repeatedly all the time and they have to develop a way of dealing with it. They have, I mean, you can't react to that as maybe I would or a patient would every time so they develop different ways of dealing with it I think

R: Mmm.

V: according to their own personalities. For some it is easier for patients to meet than others.

R: But I am suggesting that the organisation may allow a doctor to behave in certain kinds of way because, although you say it's a thinking process for a doctor to walk across the wards noisily at night, the organisation somehow permits that as an acceptable act. Yes, there may be reasons for that as you say.

V: Well they're allowed to wear whatever shoes they like. I suppose lace ups or whatever.

R: Well I, I, I mean... I meant that there may be reasons why the organisation permits an unfeeling attitude to develop

V: Mmm.

R: as a protective mechanism but that, that was your suggestion because it would be exhausting to cope with suffering all the time.

V: Well I, I was taking that into account.

R: Yes, well it's uhh

V: Well I, I mean considering the number of years I've been going in and out of hospitals, I've only really realised since that dreadful experience in the National how much doctors do vary, not only in their ways of dealing with people but, you know, adequacy in their techniques in every way - and nurses. They vary as much as any group of people outside do. Maybe not quite as much but there ought to be a way, I know, I hate to say this but that Registrar who came to take the second lot of fluid out of my brain at the National. I saw him walking across the ward, not doing as I thought he should be doing on a crowded ward, to take the fluid out of my brain with no curtains drawn. I should have said something. I wanted to say something but even I, with all my experience and what you say, you know, I couldn't.

(At the National, when I saw the registrar who was coming to take the second lot of fluid out of my brain, walking across the ward towards me, not doing as I thought he should be, I was terrified and frozen. I had the strongest gut feeling that I should not submit to this - this man should not be a doctor and he didn't know what he was doing. Numerous contradictory rationalisations crowded through my mind as to why I should not stop him - on top of which was a fear it would be more dangerous to try. The status quo, the institution - the best hospital - would prevail. This self conscious, arrogant young man was coming towards across a ward crowded with visitors, with a piece of gauze already soaked in dark brown fluid - drying rapidly - in one hand and a kidney bowl with syringe already set up with needle in the other. It was about 5.15pm, there were five visitors at the bed next to mine, three opposite and others elsewhere. He made no attempt to close the curtains round my bed and told me come and sit on the end of the bed next to him. I was aghast. I should have said something but I couldn't)

R: Why?

V: Because I wasn't sure that I was right and because I believed that my consultant who was supposed to be good would not let that man do it if he was not good enough.

R: So you had belief, an intrinsic belief in the system?

V: Yes, it was a young consultant. As far as I knew I was in the best neurology hospital in the country - if not Europe. This man surely would not be in his position if he were not pretty special. My consultant had spent about ten to fifteen minutes chatting to me, leaning against the wall near the desk, before lunch. During this chat he told me that this procedure was not a problem unless of course (he mimed) you pulled the fluid off the brain too quickly. In which case you might cause a thrombosis - a stroke - or similar. He departed with a friendly grin saying he would 'get one of his boys to do it.'

(I desperately hoped in advance that it would not be the one who came. He had two registrars.) The man in question had personality problems that were openly discussed by the nurses, who said that he constantly told them he did not have enough confidence, this they did not believe since he behaved so arrogantly. He looked and dressed as though he might be a slick dealer in the 1980s stock exchange.

He had brought me the consent form for my operation on the night I arrived. He had not expected me to read it and was very impatient when I tried. It was impossible for me to read it with him fidgeting and I capitulated to the system since I knew there would be no alternative, but I asked him what would happen if the operation went wrong (neither my neurologist or surgeon had told me about the risks of brain surgery.) He simply grinned idiotically and said "We'll make it better". I gave up and he produced a fountain pen with red ink in it for me to sign - in the circumstances it looked like blood. He then tried to get an Indian - possibly Sikh - woman to sign and gave the same responses when she could not understand it. She was unhappy and refused until her husband came in later.

I have since decided that although my consultant was or is supposed to be very bright - the pathologist husband of the woman next to me had looked up his "form" - he was still in his thirties and he probably lacked experience both of casework and of leading his team. I know that registrars have to gain experience, but he was unaccompanied and I think in view of the state of my lungs the consultant should have taken particular care. Then I feel guilty for even thinking that.

I've since formed the opinion that Ok, you know, he may be a brilliant technician and brilliant surgeon but he has not had enough experience of leading a team and he talked to me for twice as long in the morning, the consultant, as it took the guy to take the fluid out of my brain, he could have done it himself while he was talking to me. That sort of thing, you know, happens, you know. I suppose nobody's going to learn unless you're allowed to do things but...)

R: But what stopped you? What, what actually stopped you?
V: I don't know, it was a complete nightmare because as soon as he'd done it and I'd realised he'd done it practically in a second or two and I thought, am I still sitting here because the consultant had told me in the morning that of course you can't draw fluids out of the brain quickly like that.

(I think I thought his personality was too unstable and I consciously spoke to him very calmly and quickly drew the curtains myself to shut out his audience, while he was telling me not to bother it would be over in a couple of minutes. I sat down on the edge of the bed dreading it. He took ages to find the right place along my scar, when he did he dabbed it cursorily, once, with the said piece of gauze without resoaking it and set about getting the needle in. When he was satisfied he pulled the fluid out very quickly - as quickly as I would think you could get fluid through a needle - and pulled it out and showed me it triumphantly. I was sitting in shock actually thinking "Am I still here?." It was bright (arterial) red fluid and frothed to fill the entire syringe. He said "there you are - 10mls." And I thought it was considerably more. I said, still calmly "I thought brain fluid was a sort of grey colour and he agreed it was but said there was a lot of blood in this. I wanted someone else to see it but I couldn't move.)

R: Yes.

V: The consultant said, you know, do it slowly. I had a long conversation with him and then suddenly this man comes in and does that.

R: Why did you allow it to happen?

V: Are you saying it's my fault now?

R: No, no, no, not at all. Can I clarify that? I don't think it's your fault.

V: No, it's a joke. I know what you're trying to say but I can only say that most patients, without my, my experience would have been even less likely than I would to have objected.

(Reasons: There was my belief in the system, considerably reinforced by the fact that I was in the specialist hospital in the field. Also my choices about the management of my illness over the last twenty years has meant that I have not been in hospital much in that time, most of my experience of hospitals until then was earlier in more rigorous times. I personally think that procedure should not have been done outside a treatment room with a nurse present, but knew nothing about neurology and it all seemed outside what I knew about.

It seemed to me that the problems associated with the cyst in my brain were in all senses completely outside my control. It is important to me to feel that I have some control over my illness so that I can act in ways that will not make it worse, and if not healing will at least make me feel better or more comfortable. With the brain there was nothing I could do. I had tried to exercise my weak legs to make them stronger, but all it did was totally exhaust me. The messages from the brain were not getting through. I think this long and steadily worsening experience had already created a sense of powerlessness.

All this was reinforced by the way the ward in the National was run. It took only immediate pre-op and very ill post-op patients who were mostly too ill to talk to each other. The nurses when not performing necessary tasks were always at their station, talking to each other or the younger doctors. There is the story of the paralysed, blind woman opposite me who I found out did not know why she was there because no-one had told her. She, with all her limbs strapped down, wearing dark glasses and stuck two feet in front of the television all day, with a perfectly active mind and voice ignored, epitomised to me the unpredictability and sense of being wholly out of control of oneself experienced by neurological patients.

When I had the major seizure about 3 hours after the withdrawal of that fluid there was even in those split seconds as it happened a dreadful inevitability about it. The pain was of an order which I had not thought possible - it was inhuman. Electrical current not related to ones shape or previous sensations enough to fell a huge old tree. The next day it was all played down and my anger was too deep and confused to be expressed.)

R: Well what I'm suggesting....
V: But how could I have got round it? You tell me. Apart from just objecting then and making a fuss. You see, every patient thinks if they make a fuss then all the staff are going to lay into them from then on because they don't like people who make a fuss.
R: Yes.
V: The nurses don't like it, the doctors don't like it. In actual fact it's possibly the reverse. If somebody does come in and demands to be treated properly in hospital

nowadays, they usually make sure they are because they know this person's going to make a fuss if they don't, but that's very rare. Nobody knows that and I, I didn't even feel, I mean, knowing it and feeling it is two quite different things. I didn't even think that until later. I've been over that moment so many times and I'm not over it now – after nearly two years it is still a emotional drain on me and although I have wanted to write and complain I have been unable to do so. I also think that the surgeon should not have allowed him to do it in my case. I think, why should I think that arrogantly but I think that with lungs as bad as mine, that they should have taken extra care. Umm I wasn't even told beforehand that you know, there was a possibility of strokes or epilepsy with brain operations anyway.

R: So Val, you seem to suggest that not only was there the hospital, but behind that there was, there was a kind of surgical institution that's giving authority for them to do things to you.

(sorry did not really answer you here but there is another point)

(I don't know whether I can take that any further but I would say yes, and the thing that made it worse was the degree of blinkered specialisation that was going on, not only did they not take regard of my situation with very bad lungs, but they could not even write up my respiratory drugs properly the whole time I was there, in spite of several times asking for them to be corrected. This in itself caused me some degree of discomfort, before starting on my brain.)

V: Oh yes, that's the trouble, the arrogance but on the other hand you see, I don't believe that in breaking down a, a hierarchy in a visual sense, say by uniforms
R: Yes.
V: or some other basic way is going to help. I think it has, you have to maintain a structure where there is a clear line of authority and there's a clear means of working.
R: Right.

V: and I, I think you have to absolutely have that. If you haven't got that the patients will feel more insecure and I think terribly so. I don't like not even knowing who the staff nurse is, I don't like not knowing who the sister is on the ward. Basically if you're a patient, you'll probably never do it, you'll probably never talk to them but the feeling that somebody there is actually, you know, responsible

R: Yes.

V: for what's going on helps you, it's a helpful feeling.

R: Yes.

V: It's still quite frequent that you'll get a sister who never talks to the patients at all now.

R: So the structures are, you're saying are both, both helpful and inhibitory in some ways so

V: No they're not inhibitory on the patients sides. I mean, the structure itself and the line of, line of authority is good. What, what's built up behind them is a kind of an assumed position within institutions

R: Right.

V: Which I don't think is necessarily that conscious anymore in people but it, it, it's habits, die-hard and the habits can be ways of thinking not just doing things.

R: Mmm.

V: and umm I just think that if, I know that there's a cut off point where doctors, as I've said just now, need to protect themselves from breaking down in, you know, emotionally for what they see all the time but they still have in some respects to look at every patient as a person

(Appendix 3, Valerie)

Although this is one person's experience, her complex analysis suggests that such assumptive hierarchical attitudes may be alarming if exercised unthinkingly but have the potential to be reassuring when exercised as part of a co-ordinated structure that is seen to work together. This suggests that patients may pick up conflicts between agencies (nurses v doctors) rather easily and when it happens it obviously undermines confidence.

Torbert

Torbert's distinctive contribution is to "conceptualise power in terms of a theory of developmental transformation and to integrate it into a discipline for action." (Putnam 1993) He proposes four types of power; unilateral power; diplomatic power; logistical power and a blend of these three he calls transforming power. The ability to exercise and appropriately blend these four different types of power he calls "the power of balance."

This thinking is constructed around a theory of human development, seen in a description of child rearing after Rawls. At first the child will learn the 'morality of authority'. At this stage "parents unilaterally enunciate and enforce rules of conduct", which represent an application of unilateral power. Such power will only become authoritative (legitimate) with "the power to generate moral development towards principled conduct if parents:

1 make just rules;
2 give reasons for them in an understandable fashion;
3 enact the rules they enjoin when the rules apply to them as well.
(Torbert 1991 p25-26)

In adult terms unilateral power is seen as "the ability to unilaterally and uni-directionally cause the outcomes one wishes", (ibid) although it should be noted in passing that this definition of power is not exclusive to unilateral power. Furthermore, such a concept of power is not exclusive to Torbert; Lukes' first dimensional power is similar to unilateral power. However, one of Torbert's contributions is to attempt to make a link between power and justice and in doing this he concludes that unilateral power raises particular ethical issues. For example, even in a 'benign' dictatorship exercising 'benign' decisions, what will determine the right or just decision? A utilitarian approach would argue that "the right or just decision is that which generates the greatest good for the greatest number. The good is that which increases pleasure and reduces pain for each." (Torbert 1991 p17-18) Maximising pleasure and to minimising pain is to maximise utility. A utilitarian theory treats "desires as ends and reason as a subordinate and these

perspectives *implicitly* require a kind of rationality that weighs, compares, and organises desires, rather than merely calculating how best to achieve them." (ibid) Therefore, it still leaves unanswered the question, how is this to be done; how is the power to be exercised.

After unilateral power, the next stage of upbringing sees the development of diplomatic power, or peer consent. It occurs when the teenager "learns the 'morality of association', through participation on sports teams and other organizations with peers." Conduct is based more on pleasing equals than on obeying superiors and is exercised, not arbitrarily, but in the context of "organisational goals and norms that are consistent with justice." Positive experiences are associated with the principles of justice, which become explicit as the youth becomes more adult. Eventually the rules of justice gain allegiance in their own right so that "the adult becomes committed to a 'morality of principle'." (Torbert 1991 p21)

In adult terms diplomatic power is "generated not by the power wielder but by the power *yielder*-by the consent of the governed." (ibid) This is most clearly seen, Torbert maintains, in the realm of entertainment and the media. The media and entertainment personalities, who have the mysterious talent to draw mass attention, become the source of far-flung enterprises. Their power is based on others' willingness to give them attention. In this formulation, true talent represents legitimate authority because it commands the power (and revenues) associated with the willingness of the populations at large to attend to it.

Logistical power is invested in those who in office have the means to redirect benefit or otherwise to others. If unilateral, diplomatic and logistical power are the means whereby we achieve change what are the principles of justice that we adhere to in modern society? Rawl (summarised in Torbert 1991 p25-26) suggests that they are that;

1. "each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all."

2. "social and economic inequalities are to be arranged so that they are both: to the greatest benefit of the least advantaged and attached to offices and positions open to all under conditions of fair equality of opportunity."

Torbert argues that this second principle generates utilitarian results. "Inequalities of position and wealth (to which those with less would not consent, all else being equal) are to be tolerated *only* as these benefit those with less. In other words a person may consent to receive less income than another, if the additional income motivates the other to become a doctor and cure the less wealthy person. If persons with less income gain greater utility from being healthy than they would from the additional income, they would rationally prefer and choose this condition over that of having equal income but less health." This approach is based on the principle that we act as we would wish others to act towards us and "only in ways that treat ourselves and other persons as ends (never merely as means)". (Torbert 1991 p27)

By asking how each of these types of power relate to a particular conception of ethics and justice, he identified three problems that separate theory from practice. Firstly, even if a just society is created, how can one be sure that it's citizens maintain a commitment to "to just outcomes and to maintaining the necessary institutions?" (ibid) Secondly, contemporary society cannot be considered just because in the process of child rearing "few parents meet Rawls's criterion of enunciating, explicating, and enacting principled rules in child-rearing." (ibid) This is reflected in the fact that there is research to show that only a very small minority of adults in our society achieve a 'morality of principle'. Finally, he asserts that Rawls's theory does not provide a vision and method for transforming the relatively unjust and corrupt society into one that is more just and displays greater integrity?

He then argues that to transform such a relatively unjust society requires a kind of power that goes beyond the unilateral, diplomatic and logistical kinds of power. He suggests that to do this requires a *blend* of the three types of power, which he calls 'transforming' power. The particular character of transforming power is adherence to the concept of

'mutuality'. A person exercising "*transforming power invites mutuality*- a mutual exercise of power guided by a living awareness of what is currently at stake for the particular systems participating in the transformation". This involves co-operation from "the inside and the outside" and its operation "*requires a continual, humble effort-not just to be rational, but to be aware of the present moment in all its fullness.* This awareness effort includes and transcends one's own material interests, emotional preferences, and intellectual theory about the situation, as well as those of others and the institutions involved. It also transcends the narrowness of the present and experiences how the past is growing into this moment and the future is growing out of it." (Torbert 1991 p29) Torbert finishes his arguments by relating each of these stages of development to different leadership and management styles. Opportunists, Diplomats and Technicians construe power as unilateral, diplomatic and logistical respectively. Those who reach the stage of 'achiever' are able to integrate these three forms of power but to be able to 'exercise' transforming power requires development beyond the achiever to Strategist, Magician and Ironist styles.

Torbert's other contribution was to link these developmental stages, types of power and the exercising of them to different time frames. Immediate opportunities and emergencies often call for the use of unilateral power, equivalent to the opportunist stage of development. When tasks and role related procedures are routine, institutions give predetermined consent to undertake and fulfil these. Such is the role of the Diplomat and Technician. The time frame of these tasks undertaken by Diplomats or Technicians are a year or less with "primary excitement from carrying out three to nine month logistical projects." (Torbert 1991 p73-75) Achievers and Strategists seek real underlying meaning and consider time frames of three to five years. Magicians and Ironists will be "pre-eminently attuned to creating contexts for inquiry into the real call of organizational mission and into full experience of organizing across territories of purpose, strategy, operations ,and environmental impact" and not uncommonly consider time frames of seven to twenty one years. (ibid)

Putnam and others drew attention to two dilemmas inherent in this construction. (Putnam 1993) Firstly, "one can only appreciate those meanings that are at one's own stage or below. It is difficult to research higher stages, both because they are rare and they may exceed the researcher's capacity to understand." The second dilemma concerns one of practice. It becomes easy for those who have achieved higher stages to devalue others who are at a lower stage. It may, for example, be hard to maintain a degree of mutuality in the face of an entrenched opportunist. At one level these appear to be major criticisms but I find myself wondering if the answer to them cannot be found in the time-scales in which such stages operate. The time-scales themselves reflect the time it takes developmentally to understand different sorts of power. Unilateral power employed by the opportunist is immediate. This is what the small child understands. Magicians and Ironists exercise 'transforming' power and utilise time frames of seven to twenty years. Without necessarily having recourse to any specific practice of my own, I can see how individuals, teachers and parents, have transformed my thinking and experiencing in a way that has created my current interest in inquiry. This transformation was undertaken with a purpose, strategy, operation and environmental impact, all components of transforming power. This thesis is largely about understanding transformations that I have undergone, transformations that have both enhanced and limited my view of the world. This insight, made over a period of time, make me gain glimpses of what is meant by the concept of transforming power.

How does Torbert's concept of power reflect itself in clinical practice. As indicated at the beginning of this section, his concept of power may be reflected in the various frameworks of practice I have begun to find useful. These frameworks are summarised below. Although a more precise explanation of these various models and how they came to be developed will be presented later in this section, it can be seen that the pattern is one that starts from complete separation of researcher and researched and progresses through to mutuality.

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator
Type 3	Observer/researcher	Observer/researcher/participator
Type 4	Observer/researcher/participator	Observer/researcher/participator

I can see in general terms a relationship between Torbert's concept of power and the models of clinical practice I espouse. In the same way that Torberts construction of power developmentally progresses from unilaterality to mutuality, these frameworks have developmentally broadly tried to do the same. In type 1, when the doctor acts as observer/ researcher and the patent acts as an observer/ participator, the doctor could be said to exercise unilateral power. This is the kind of mode of practice I was encouraged to undertake as a young newly qualified doctor. Such a model ignores the role of disease context, emphasises the importance and significance of disease pathology so that the pathway from history to examination to diagnosis and treatment is one that is largely controlled by the doctor. At the other end, a type four framework would suggest an approach to mutuality, the espoused position of the strategist and beyond. In the same way that Torbert noticed that strategists employed unilateral, diplomatic and logistic power in a blend he called transforming power, I notice that in type 4 frameworks it becomes possible as a doctor to once more exercise unilateral power once more. This is an argument I propose to develop later. Similarly type 2 models, which I called the 'consumerist' model where the doctor invites the patient to make a selection from a number of choices, bears a resemblance to Torberts diplomatic management style.

Some selected philosophers on power

It is clear that in each of these four broad approaches of Clegg, Marshall, Vince and Torbert, the authors have drawn on the work of a number of theorists on power. These include particularly those of French and Raven, Lukes and Foucault. I propose examining these in a little more detail.

French and Raven

French and Raven relatively straightforward classification of power identified five types.

- reward (the ability to reward to different ways)
- coercive (the ability to punish in different ways)
- legitimate (the perception of power as a right)
- referent (the perception as being liked, charismatic) and
- expert. (the perception as being knowledgeable).

(French & Raven 1959. p155-165)

These different descriptions of power are based upon the assumption that there exists in organisations many different individuals and groups seeking to influence others in an effort to achieve certain goals. Clegg's model might regard reward, coercive and possibly expert power as examples of episodic power exercised by agency in pursuit of agency objectives. Vince drew attention to a special kind of legitimate power white middle class men assume upon themselves and noticed the discursive power of experts in the way that they might use language. Marshall explicitly recognises the contribution of French and Raven in developing her first dimension power usually seen in organisational reward systems, but extended the idea to consider the power of *access* to these reward systems as well. Finally, Torbert might see reward and coercive power as examples of unilateral power, referent as overlapping somewhat with diplomatic power and legitimate power invested in those offices able to exercise logistic power.

Doctors, by virtue of their position, can exercise expert power. However, French and Raven observed that when the expert is not a member of the same group, doctors and patients are members of different groups, then 'expert power' is more accurately described as 'informational power'. This distinction may be important because the exercise of power in this context is based upon *change* of one party by another. 'Informational power' alone will not be sufficient to generate change unless it is believed

by the receiver to be credible. Credibility may be linked to a doctor's legitimate power and, in this way, informational power may be enhanced considerably. Credibility will also be based upon "characteristics of the stimulus such as logic of the argument or the 'self-evident facts'"(French & Raven 1959. p164) and in this respect is dependent upon the nature of the discourse between the parties. Furthermore, the regard society pays towards doctors, reflected in the 'ceremonies' that characterise outpatients, wards and the operating theatre, may enhance credibility even further. Expert power is therefore informational power that is credible. However, as well as being credible in its own right, the information, which forms part of the stimulus, must be seen to be within the boundary of the expert's experience. So that it must be concluded that expert power is credible, informational power within a boundary delineated by the field of the expert's knowledge.

If the expert attempts to influence another beyond the boundary of the expert's knowledge and this is not regarded as credible by the second party, this may result in some undermining of the expert's power because the notion of trust is challenged. The trust arises out of an implicit understanding that expert knowledge is offered firmly within the boundary of the expert's knowledge. The second party may not accurately perceive when the boundary has been reached and so if the expert is considered to have crossed it, it may then call into question the reliability of the core expert knowledge itself. From that point onwards, the second party may chose to question all information that is imparted. As such, the boundary circumscribing expert knowledge is thought to be more clearly defined than say the boundaries of referential or coercive power.

This suggests that as an ear, nose and throat surgeon, my expert's knowledge would become less credible if I were to extend beyond the accepted boundary of this specialist knowledge. It might be challenged if, for example, I offer an opinion in the field of respiratory medicine and certainly if I extend beyond the boundary of medicine altogether and offer an opinion upon the life and lifestyle of the patient. When experts manage to offer and have accepted opinions outside their area of expertise, French and Raven called this the 'halo effect'. What are the implications of this in the clinical situation when doctors cross the boundary, which delineates their 'informational power'? How does the

'informational power' interact with knowledge that the patient may have about their own lifestyle and wish to bring into the decision making equation?

I was taught as a medical student that a characteristic of a 'good' doctor was to take into consideration the occupation and lifestyle of the patient when considering treatments. In principle this represents an attempt to place treatment in context. As such it can be no more than an attempt to develop an imperfect understanding of the lifestyle of the patient. A positivist might see such lifestyle context as not especially important (it is usually marginalised as bias). A constructivist would argue that such context is very important and the principle expert in the understanding of such context must be the patient. As an espoused constructivist, I would adopt the latter view, but it still leaves the problem of how expert, informational power of medicine interacts with expert, informational power of the patient and their lifestyle. Another framework for decision making is needed.

A constructivist perspective allows me to argue that when the relevance of the disease and treatment needs to be judged within the life of the patient then the patient must take over as 'expert', expert in their own lives. The basis of this is that it is generally easier for the patient to cross the boundary into the specialists 'information' domain and obtain information to influence treatment decisions than the other way round. A doctor would provide a biomedical analysis of the clinical problem and offer treatment in a series of options, each with their pros and cons, and invite the patient to make a selection. This approach forms the basis of the second decision making model, the 'consumerist' model.

Framework 2

	Doctor	**Patient**
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator

For example, there is a condition called otosclerosis, which results in a slowly progessive hearing loss. The cause is increasing fixation of the stapes, one of the ossicles

that connects the eardrum with the cochlear. A type two approach would include a description of the problem and a list of possible options, which might in this case include no treatment, the use of a hearing aid or replacement of the fixed ossicle with a prosthetic ossicle. The last surgical option carries with it a risk of 3% chance of a total hearing loss in the operated ear. The patient would be expected to 'research' their attitude to this risk analysis problem by determining what day to day problems occurred as a consequence of the hearing loss, and how well these were managed with the use of a hearing aid. Armed with this information a patient might over a period be able to decide on surgery or not. Such an approach is represented diagramatically in **Figure 5.**

Expert power is based upon information, the ability to provide information or 'informational power' and the above would suggest that the expert would demonstrate such expertise by giving such information. Evidence suggests that "the professional is jealous of his prerogative to diagnose and forecast illness, holding it tightly to himself. But while he does not want anyone else to give information to the patient, neither is he himself inclined to do so" (Friedson. 1970. p143) A number of suggestions have been made as to why this should be so. Lack of time, inability on the part of the patient to understand, failure on the part of the patient to remember what was said, objections concerning the ethics of conveying bad news and finally the difficulty about doing so have all been suggested. (Tuckett 1985. p199) An further view is to consider expert information as a logistical resource, which is redistributed with care. The claim to a monopoly of expertise and knowledge has been one of the foundations of the professional's claim to a privileged social and economic status and not one, it is argued, that will be given up lightly. Moreover, "a degree of mystification and admiration in the client, along with a devaluation of lay knowledge, is sometimes thought to bolster professional power" (Tuckett 1985. p5) This suggests that there might be good reasons why doctors control scarce knowledge in order to act omnipotently."(Tuckett 1985. p213) This attempt to maintain 'mystification' might perhaps be thought of as a remnant of the 'magical' component of the medical transaction.

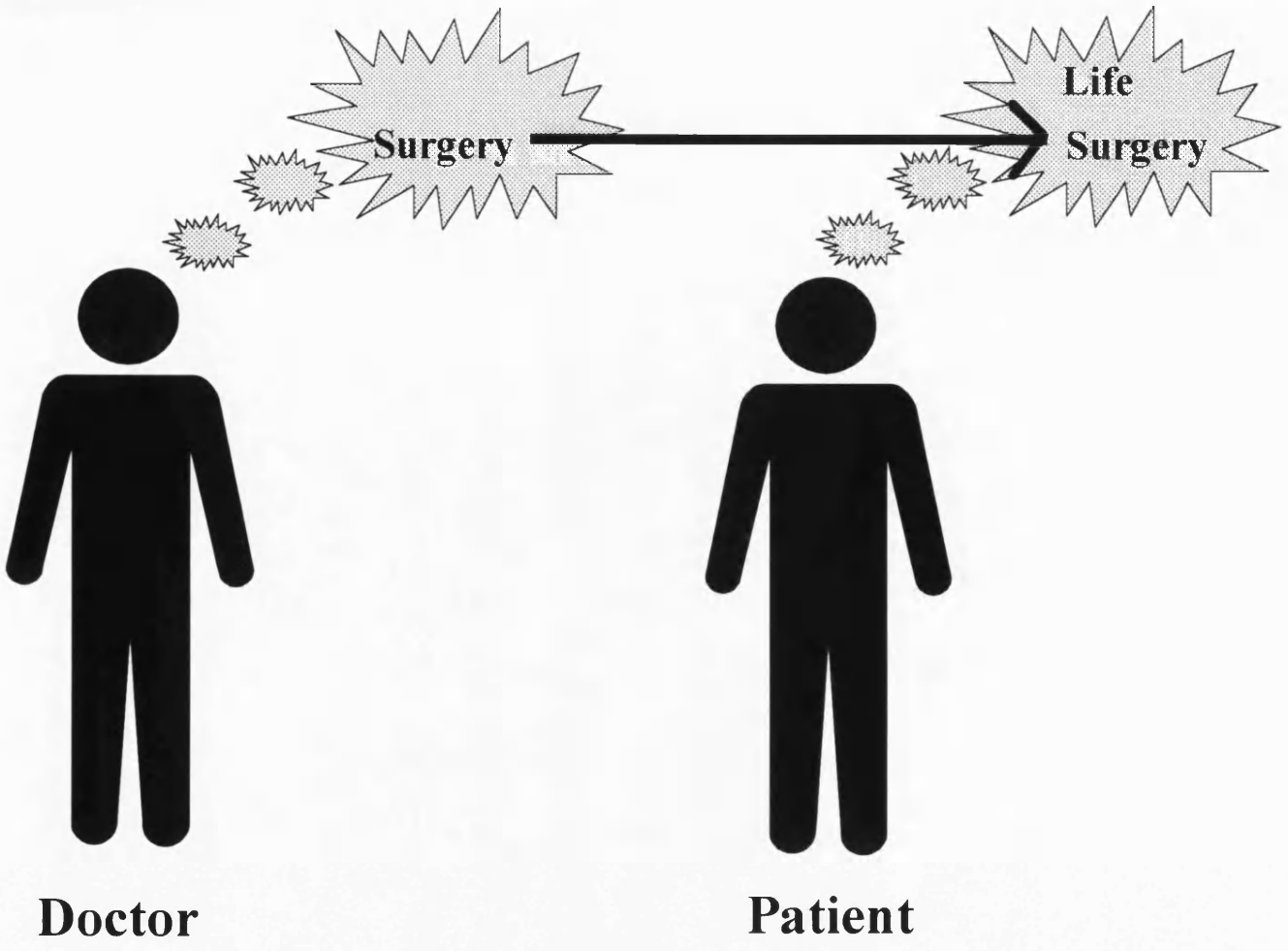


Figure 5. Type 2 The Educator/Consumer

It might be easier for the patient to take medical information and judge its relevance to their lifestyle than the other way round

I cannot leave an analysis of the nature of 'expert power' without reference to the 'sleeper effect' but it's understanding involves an appreciation of the nature of 'referent power'. Referent power is based upon the identification of one person with another, in this case it might be the charisma felt for a particular doctor. If an individual doctor has positive expert power but negative referent power then the change expected from the application of expert power might not be forthcoming. French and Raven expounded the belief that "over the passage of time the subjects tend to forget the identity of the negative communicator faster than they forgot the contents of his communication....there was a weakening of the negative referent influence and a consequent delayed positive change in the subject's beliefs in the direction of the influence attempt ("sleeper effect")". (French & Raven1959 p164). They put forward experimental evidence to support the idea that if the negative communicator was reintroduced, it reinstated the negative effect on change in belief once more.

One would suppose that a doctor with negative referent power would find that they would change another's behaviour over a period of time as their poor communication skills were forgotten, provided that the patient did not come into contact with them again. The stories of David, Patrick and Valerie would not necessarily support this view. Each recounted experiences of contact with doctors that was unsatisfactory at the personal level and who might have been considered to have negative referent power, and my analysis was that this rather made them question the nature of the expert or informational power given to them. Some of their stories took place over a time-span of several years and didn't seem to display any weakening of the negative referent effect.

Doctors might also be expected to possess 'legitimate' power. "An influencer O may be seen as legitimate in prescribing behaviour for P because he has been granted such power by a legitimizing agent whom P accepts." (French and Raven. 1959. p160) Legitimate power in medicine is based upon the publicly owned regulations of the General Medical Council and the various Royal Colleges. These agencies invest their representatives with legitimate power, which probably explains why it is common practice for certificates to be publicly displayed in offices. It might also explain why they are so large. My

fellowship certificate of the Royal College of Surgeons measures 60 by 45 centimetres. Legitimate power is said to be more robust, stable and consistent than referent power but is still dependent upon the correct application within a 'specific set of regions'. Where do these boundaries begin and end? The agencies attempt to influence public policy of smoking, eating and exercise in the political domain and their representatives echo this by commenting upon smoking habits, eating habits, weight control, exercise in the clinic. This 'disciplinary' network suggests that legitimate power is invested in practitioners in return for adherence to the party line on policy. A type 2 model might challenge such a practice because this suggests a patient is entitled to argue that it is in his or her interests to continue smoking, not exercising and eating high fat foods.

Lukes

Lukes saw certain individuals and groups as occupying a disadvantaged position in society by virtue of class, gender and race. He put forward a three dimensional description of power.

- First Dimension. In which one individual or group forces another to do something.
- Two Dimension. In which one individual or group controls what comes into the agenda.
- Three Dimension. In which one group or individual controls the world view of others. (Lukes S. 1974).

Lukes' concept of power is an all embracing "restrictive agency model" that arose out of a critique of Dahl's formal model of power, the ingredients of which were found in classical mechanics. The emphasis is on a prohibitive 'power over' concept of power. Some have suggested an alternative 'power to' capacity or dispositional concept of power. This alternative conception is centred on a view of power that was capable of implementing certain enabling and disabling strategies vis a vis protagonists, should the occasion arise. (Clegg 1989 p86) This distinction itself suggests that power cannot be

regarded as a unitary concept and challenges the single model of power put forward by Lukes.

Each of the pluralist conceptions of power outlined earlier acknowledge the importance of Lukes' model. Clegg's framework of power explicitly draws upon the work of Lukes but takes the model to task for failing to address the notion of 'best interests' adequately enough. Marshall refers to one sort of power as 'power over' others. Torbert tries to link power to justice. He puts forward a model that tries to pay attention to purpose (justice) and strategy (the exercise of power) in a way that draws attention to the notion of 'best interests'.

My first reaction on encountering Lukes' model was that it was particularly relevent when considering an understanding of power in a clinical situation. First dimensional 'positivist' power might be exercised in emergency situations, when a doctor attempts to coerce patients into adopting a course of action or when patients refuse to follow a course of action suggested by the doctor. When David went to London to seek a second opinion, the surgeon offered an opinion of what should have been done and David was told he "was mad" not to accept this advice. The doctor is attempting, unsuccessfully in this instance, to exercise first dimensional power. Similarly, Patrick was advised by a surgeon that he ought to have radiotherapy after the tumour on the head had been removed but he declined to accept such advice. In a vivid example, when on this occasion first dimensional power was successfully implemented, Valerie was sitting on the ward when a doctor took fluid from her brain.

When I saw the registrar who was coming to take the second lot of fluid out of my brain, walking across the ward towards me, not doing as I thought he should be, I was terrified and frozen. I had the strongest gut feeling that I should not submit to this - this man should not be a doctor and he didn't know what he was doing. Numerous contradictory rationalisations crowded through my mind as to why I should not stop him - on top of which was a fear it would be more dangerous to try. The status quo, the institution - the best hospital - would prevail. This self conscious, arrogant young man was coming

towards across a ward crowded with visitors, with a piece of gauze already soaked in dark brown fluid - drying rapidly - in one hand and a kidney bowl with syringe already set up with needle in the other. It was about 5.15pm, there were five visitors at the bed next to mine, three opposite and others elsewhere. He made no attempt to close the curtains round my bed and told me come and sit on the end of the bed next to him. I was aghast. I should have said something but I couldn't)
(Appendix 2, Valerie)

It could be argued that third dimensional power is evident here as well. There are all sorts of factors that exert three dimensional power to silence Valerie in this situation. These include organisational such as staff uniforms, professional routines, the public nature of the encounter, surgical smells on the ward, and the implied withdrawal of resources, including expertise, if the patient fails to be 'obedient'.

In first dimensional power, conflict is overt and the situation is analysed in terms of behaviour, concrete decision making and resolution of real issues; in other words something has to be done by A in the face of B's conflicting wishes. Lukes saw A's as having power over B largely through A's control over superior bargaining of resources and this suggests that failure to submit to A's wishes may lead to withdrawal of A's resources. (Clegg 1989 p90) This might explain why it is common for patients to express concern over what might happen if they chose to disregard advice given to them by doctors. Many are worried that doctors will react unfavourably and they, as patients, may be denied access to medical resources at some future point in time. For example, patients are often concerned at what would happen if they cannot accept a specific date for surgery. They ask if will be taken off the waiting list entirely for refusing to accept.

Second dimensional power is said to take place when the agenda is controlled by one party in order to influence non-decision making. In such a situation conflict is avoided, becomes covert and conflict issues remain only potential issues; they never fully manifest themselves. Non-decisions (overlooking for a moment the unmeasurability of non-decision making) are said to be made which are only understood in terms of interpreting

an intentional action. Given such a situation, it is not possible to be certain that non-decision making has ever taken place with patients in the clinical situation. This position can only be inferred from data and this inference cannot, by its very nature, be validated by inquiry on my part. To do so exposes the non-decision making strategy, which reformulates the situation into a first dimensional power situation. However, I am aware as a doctor that I may be trying to control agendas in order to influence non-decision making. So that in the description of a surgical procedure, I am aware of being able to make selections of what should and should not be included in such a description in order perhaps to influence the emergence of potential issues. For example, in the independent sector in medicine, financial renumeration is considerably higher for surgical procedures than it is for consultations. The payment for undertaking a tonsillectomy is £240 for thirty minutes work and there no expenses incurred by the surgeon in the procedure. The same payment for a consultation is £70 for which there may be expenses of £20 or £30 for secretarial and room hire. It is evident that if a patient elects to have surgery, the financial renumeration is much more attractive to the surgeon than if they chose not to have surgery. Understandably, this could be an issue that colours the way that the advantages and disadvantages surrounding surgery are portrayed and yet this influence is usually successfully kept from surfacing. No patient has ever asked me the legitimate question; Does the fact that you will be paid very well to perform this surgery on me, influence the way you present the case for surgery?

As a practitioner, I can see that I might use two dimensional power to control the agenda, limit the exchange of information and anticipate key issues before they emerge and try, if felt appropriate, to divert or block them. Others have also suggested that the doctor withholds information to ease the workload and shorten the consultation and patients use it to attain an end such as a desired prescription (Lorber 1975. p213). Tuckett observed "that both doctors and patients may limit what they say more in the interests of achieving their aim than in helping the other to understand their point of view." (Tuckett 1985. p6)

Are there any procedures that make control of agendas easier? I am not sure but I have a sense that the use of 'structures' in clinical consultation might help. By structures I mean

the way that a consultation proceeds with a recognised order of history taking, examination, investigations, diagnosis and discussion of treatments. I notice that I am more inclined to interrupt a patient when they depart from this structure. I may not be alone in this feeling for studies of clinical consultations have shown that doctors interrupted their patients opening statement in 77% of occasions (Beckman & Frankel1984.p692-696). A structured way of conducting a consultation is taught to medical students at an early stage, almost from the first day they arrive on the wards. Great emphasis is placed on sticking to this order so much so that when a medical student is examined for finals, evidence of 'structure' in the presentation of any knowledge is at least as important as the medical content of the answers themselves. Perhaps they are empowering structures, What Gordon called "control through rationality." (Gordon D. 1988. p19). How do I know that structures are empowering? Because sometimes they disappear and unstructured interviews make me more unsure of my role. If the patient starts to cry, or gets angry, and the interview departs from a structured format, it seems to leave everyone unsure what to do next and certainly I am conscious of suddenly feeling disempowered.

Finally, since second dimension power is about controlling agendas, which also includes control of time, mention should be made of the many ways that one can have to indicate that the consultation has come to an end. These techniques may oblige the patient to finish before they have obtained all the information they might wish to receive. This may include loss of eye contact, a shift to a non-medical topic suggesting that the business is over, interruption by the clinic nurse or offering a handshake. Is there a situation when these games cannot be played so easily? When the patient is a doctor as well, it might be argued that the patient is able to more easily recognise techniques used to control information, techniques that could conceivably enhance non-decision making. So that when a doctor sees another doctor as a patient, any limit on the time taken to fully discussed the problem is eased and such a consultation I sense from my own practice takes much longer. There may be other reasons, discussed earlier, why this should be so.

Three dimensional power is when A controls the worldview of B and strives to keep conflict latent so that B appears to move autonomously. A supposedly determines the 'real interests' of B. Understandings are achieved in this situation by analysing political agendas and information structures. For example, a doctor strives to determine what happens to a patient by constructing a whole worldview of information in such a way that suggests to the patient that only one choice of action makes sense. Similarly, the doctor is under the same process because medical establishments set up principles of good practice that serve to determine how these medical world-views are constructed. The doctor might believe that he or she is practising autonomously but in fact practice is shaped by education, hospital working environment and the rules of conduct of the General Medical Council.

How do doctors construct medical world-views for patients? It seems to me to revolve around re-constructing for the patient a socially sanctioned dominant view of the clinical problem in biomedical terms. The problem is translated from a problem described in terms of everyday words and similes to a biomedical description of pathophysiology. This shift to medical discourse constructs a world-view for the patient, which I would maintain is then better understood and shaped by the doctor. "The physician wants a biomedical definition, in terms of a disease with known physical manifestations, which implies medical ownership, while the patient wants the definition to be in his or her own terms of the illness experience" (Mischler 1984). This intellectual property then 'belongs' to the attending physician. This has, I would suggest, been developed to such a degree in contemporary society that a hegemony exists that provides the principal medical outlook for the whole of society. Can I credibly support this assertion with a typical example?

Consider what happens when a small child comes to the clinic with a hearing loss. This 'everyday' problem would, after one visit, be turned into a 'medical' problem of 'middle ear fluid' or, even more pathophysiologically, 'serous otitis media'. Hearing loss is described in terms of decibel loss at different frequencies. Pathological changes in the eardrum are described as Tos stage 1,2,3 or 4. Speech problems are described as

problems of central processing. Once this transformation has been made, then management decisions are based on research that has only measured these parameters. Patients do not have easy access to this language and this research and in this way control is exercised.

When attempts are made to translate the problem or the management decision from biomedical language back to everyday language, the metaphors used 'to explain the problem' may sometimes be seen as generating worry, and possibly dependence, by emphasising the importance and severity of the problem. For example, hearing loss in small children may be due to the presence of middle ear fluid. Such fluid is often referred to as 'glue ear'. The use of this metaphor prompted me to start asking patients what such a description meant to them. It quickly became clear that its use conveyed the idea that the highly delicate middle ear mechanism was 'glued up'; 'araldited up' as one mother said. This is an inappropriate mental image because the middle ear space is really part of the back of the nose and the fluid is more akin to saliva and not at all like glue. Deconstructed like this the problem sounds almost trivial so one is left asking whether the development of more worrying terms like 'glue ear' may be part of a subtle use of language to encourage certain courses of action rather than others. Wrong asserted that "the professional has gained a status which protects him more than other experts from outside scrutiny and criticism and which grants him extraordinary autonomy in controlling both the definition of the problems he works on and the way he performs his work." (Wrong 1979 p337)

Patrick voiced his suspicions that doctors construct arguments to encourage patients to adopt treatments that may not be in the patient's interests but protects the doctor from future litigation.

P: *Excuse me Richard. I think that's a different issue because you were at that time, and I can understand, believing that this was not the source of the cancer and I can understand the medical argument*
R: *Arguments for it.*

P: *Yes, were in fact against that being the case, supported by the fact that three other doctors said exactly the same thing with the same conviction so I understand that. Uhh the problem arises when the, when it's removed and it's found to be cancerous then in fact we have to decide uhh why it's cancerous. Is it*

R: *Yes.*

P: *associated with the previous cancer? It's always been cancerous and it caused the previous tumour? Or it is another, it is a spurious event which has created a new cancer. So these, these are different analyses as far as treatment is concerned.*

R: *So what you're saying is that people have decided to go ahead with radiotherapy to cover themselves as it were and therefore they construct an argument*

P: *That's a terrible thing for me to say.*

R: *xxxx*

P: *But yes.*

R: *They construct on argument based around the idea that, that this must have undergone malignant change in the last two or three years*

P: *It was another factor, another factor which created the envelope of confidence.* ***(2)*** *This might have been the case*

R: *Right.*

P: *and if it, if it had been the case then my argument uhh relating to the truth of the history of that uhh cancer, would carry and there would be no need for radiotherapy.*

R: *Right so you, you in other words you were able, am I right in saying, you were able to, to see through the the uhh the constructed world of medical knowledge to see why, why that had been done because you were, you were given a series of arguments that created a good medical reason for going ahead with radiotherapy but you were able to see that that was a constructed world because doctors were then able to do what they really wanted?*

P: *Yes.*

R: *without entertaining other possibilities*

P: *Yes.*

R: *because you felt were the genuine ones.*

P: *Well I thinks that's another arm to this actually which is that radiotherapy, sorry if*

you had a tumour, ***Remove it-radiotherapy!***
(Appendix 2, Patrick)

It would seem, according to Lukes, that some social groups are generally prevented from achieving a correct understanding of their situation because they have passively accepted an illusory account of reality that prevents them from recognising and pursuing their common interests and goals. If that is the case, then who or what determines real interests and how is the possibility of our knowledge about such real interests realised? Lukes maintains that "men's wants may themselves be a product of a system which works against their interests, and in such cases, relates the latter to what they would want and prefer, were they able to make a choice." (Lukes 174: p34). He is suggesting that it is possible for power to be exercised over an agent against its preferences but in its real interests or against their latent interests. This assertion strikes at the centre of one of the major assumptions that I have held as a doctor for many years. If, some years ago, I had been asked the question, how do I know whether I am working in the real interests of the patient, I am quite sure that I would have failed to understand the significance of the question. "Of course", I might have replied, "isn't that what a doctor is supposed to be doing. Why do you ask such a question?" The complexity and difficulty of answering such a question is made transparent by Clegg's critique of Lukes in a number of ways.

Lukes takes the view that it is essentially responsible individuals, who are the agency exercising choice at the heart of the structures of power. "Agency, conceptualized in terms of moral responsibility, is the locus of individuals who chose their actions under conditions of more or less relative autonomy. Their responsibility is to choose whether to act in terms of their own selfish interests or some conception of the real interests of broad segments of society as a whole." (Clegg 1989 p98) Such choice, however, entails responsibility and this responsibility is not defined other than in terms of a responsible agent serving broad social interests. Clegg has critiqued this position in three main ways.(ibid) Firstly, he suggested that interests "are self ascribed preferences" whose existence can only be revealed under "conditions of relative autonomy and democratic participation." In other words it is insufficient to claim to be acting as a benign agent; a

structure of liberal political participation is also a requirement to assist in demonstrating that this is so. Secondly, there is no ethical framework on which to base any position. Finally, real interests may only be understood in moments of "extraordinary action" and are not usually understood during the more usual situation of subordination. This last point is especially pertinent because it seems to me that the power underlying the stories and experiences of all three patients described, David, Patrick and Valerie, is rooted in the "extraordinary action" that each find themselves. They are all confronting an end to their existence and this may have triggered, in these cases at least, a determination to exercise their real interests. David, when asked how he would have responded to a surgeon who might have insisted on treatment he regarded as not in his real interests replies:

D: *Yes I would (have blocked that), without a doubt. I think uhh* ***(2)*** *if, if, if you, you look at structured Western civilisation there are all sorts of organisations who would dearly love to run your life for your and (Laughter)*
R: *Right.*
D: *and try to on regular basis and, and I'm cognoscente of the fact that you, you could be aware of it all the time, uhh, so no I, I wouldn't be forced down any particular route I don't think.*
(Appendix 1, David)

Patrick resorts to a careful study of risk in order to block the idea of follow up radiotherapy, which he feels inappropriate. Although this is not fully portrayed in the interview, Valerie has since explained that she is proposing to decline the suggested heart and lung transplant in the belief that she will live longer without such surgery.

These situations are in my experience relatively rare and in the vast majority of clinical situations I encounter the opposite seems to be prevalent. A sense of powerlessness to question the medical hegemony of the day seems to be present. As Clegg has commented Whitt (1979), Katznelson (1973) Pateman (1970) Freire 1972 and Garson (1973) have all identified this sense of powerlessness. (Clegg 1989 p109) In suggesting causes for it,

they point out that powerlessness may act as an indirect mechanism of third dimensional power and Valerie's experience recounted earlier seems to support this. Those who lose a lot may give up trying to win after a while and apathy or fatalism becomes the norm along with acceptance or resignation. Some may decide it is better to participate than resist and finally resisting all the time results in chronic disorganisation.

What is my practical reaction to this position? I began to become aware of two distinct changes in practice. Firstly, right at the beginning of a consultation I will make an attempt to ascertain what the patient regards as their real interest in coming to the clinic. Questions like, 'What are you hoping to gain by seeing me today?' act to focus for a moment on what are perceived as real interests and this stance has been alluded to earlier in a discussion on framing. Secondly, an attempt is made to undermine the hegemonic view of medicine. This is done by suggesting that whilst I may be an expert in a certain area of the body, I would regard the patient as an expert outside this clearly circumscribed domain. They are invited to express and to hold onto any opinion they might have about what is a right and proper course of action for them to follow. This pays attention to the circumscribed nature of expert power of French and Raven, and is at the very least a shift towards mutuality by suggesting that a meeting of experts is taking place. "A person exercising *transforming power invites mutuality*- a mutual exercise of power guided by a living awareness of what is currently at stake for the particular systems participating in the transformation. *Transforming power* cannot be insolently and unilaterally wielded."(Torbert 1991 p57)

So far I have only addressed the extent to which I, as a doctor, have become aware of the way in which I can exercise third dimensional power. I am inevitably prompted to examine to what extent are my thoughts and actions are the subject of third dimensional power themselves, the third dimensional power of the medical establishment? Whitt has proposed three models of group power.

Pluralistic model	interest groups
Elite model	institutional elites
Class dialectical model	social classes

Whitt quoted in (Clegg 1989 p104)

Whitt also proposed a series of criteria when examining political issues to justify inclusion in one or other of these models. The tests for the elite model suggests that medicine falls into this category.

a. a high degree of elite involvement
b. general convergence of interests among elites
c. elite study and dominance on the issue
d. stability of the political allegiances
e. outcomes that tend to favour elite interests
(ibid)

If the elite group is successful enough, then hegemony occurs so that the "intellectual, moral and philosophical leadership provided by the class or alliance of class and class fractions which is ruling, successfully achieves its objective of providing the fundamental outlook for the whole society." (Clegg 1989 p105) In this situation members of the elites themselves may be captives of the elite interests. Is this how I now see myself?

I am not sure, but the recent changes in the National Health Service has provided an interesting period in which there has been an attempt to destabilise the medical elite group by threatening the interests of a subgroup, hospital consultants, within the broader medical establishment. The reason for this is that the whole emphasis of 'Working for Patients' (HMSO 1991), a strategic change document for the National Health Service, was on the importance of a primary led healthcare system. This meant that a particular hierarchical group within the elite was challenged by these changes. The ideas expressed in Working for Patients challenged an elite by espousing the notion of competition between hospitals and what is noticeable is how this has manifestly failed to happen in

the last few years. This suggests that in this case elite cohesion is fairly robust. How has this change been resisted?

Whitt thought that elite models were dependent for their stability on a number of factors. The principal factors here were non-competitive business interests and elite cohesiveness. Despite the many changes that took place those engaged in national health service and private practice continued by and large to confine their practice to patient populations of well circumscribed areas. In other words competition was avoided. Secondly, informal networks such as the Royal Colleges and Royal Society of Medicine provided forums in which professional elite interests were discussed. What I felt I was observing was the power and effectiveness of an elite group maintaining the status quo. I also noticed how caught up I became in the process. I constantly paid attention to best interests at a number of levels; those of myself as a doctor, those of myself as a patient, doctors in general, my own hospital, etc. Despite giving much thought to the problem, I could not find consistent ground on which to make a solid stance as to what constituted a justified position.

These are all obviously assertions I make as a professional practitioner but finding data to ground this suggestion and convince others (an assertion I make as a researcher) I notice is difficult. As Clegg has observed, "individuals cannot recognize whatever their real interests are as long as they are subject to distorting dominant ideologies. Such dominant ideologies ..mask true needs with false wants...the problematic of 'hegemony' and the 'dominant ideology thesis' develop from this perspective." (Clegg 1989 p127)

Foucault

My interest in a perspective of power based on the work of Foucault arises from his analysis of power in three ways. Firstly, in his concept of disciplinary structures. His work 'The Birth of the Clinic', together with 'Discipline and Punish; The Birth of the Prison', charts how these organisations established disciplinary structures that permeated

throughout these organisations and served to influence and control individuals who adopt marginalised positions. He took the view that there may be dangers in such control and that it may be appropriate to offer certain forms of resistance. Secondly in the relationship he draws between power and knowledge. In doing this Foucault argued that certain discursive practices arose that were structured in such a way as to determine "which statements were intelligible; which of those statements should be counted as serious; who was empowered to speak seriously and what questions and procedures were relevant to assess the credibility of those statements that were taken seriously." (Rouse 1994 p103) Thirdly, his observation of the relationship between space and power has relevance to my practice in the world of medicine because of the way that hospitals are physically constructed as expressions of power, both in the clinic and the ward. The way in which hospitals have been laid out according to medical disciplines, in vast wards lacking in privacy, and even in the way that individuals move within them, are all subject to an analysis of power.

The concept of power discussed to date of French and Raven, and Lukes are essentially familiar ones of the A influencing B type. Foucault presents a different concept of power "as somehow present in its absence from the social terrain, in the normal routines of everyday organizational life generally." This initially bizarre idea contrasts with the more usual conception of sovereign episodic power where power "means that something has to be seen to have been done in order for it to be said to be exercised." (Clegg 1989 p149) His interest was aroused by observing the difference between massive but infrequent exercises of destructive force (public executions, military occupations, the violent suppression of insurrections) and the constraints imposed in practices of discipline and training. Foucault's contribution was to describe the transformation that took place both in scale and continuity in the exercise of power. He documented this shift in political practice from the display of power as spectacle to the exercise of power through making its target more visible and audible. There was a gradual development of techniques of surveillance. (Rouse 1994 p95) In his own words; "It was a question not of treating the body *en masse*, 'wholesale', as if it were an indissoluble unity, but of working it 'retail', individually: of exercising upon it a subtle coercion, of obtaining holds upon it at the

level of mechanism itself-movements, gestures, attitudes, rapidity: and infinitessimal exercise of power over the active body." (Foucault 1977 p136-137)

Foucault then conceives "power as a technique which achieves its strategic effects through its disciplinary character." (Clegg 1989 p149) Methods of surveillance and assessment first developed in state institutions such as prisons, became widely disseminated through schools, the army, the asylum, and the capitalist factory. They become strategic to the extent that they are effective constitutions of powers "because they are knowledge constituted, not just in texts but in definite institutional and organizational practices, they are 'discursive practices': knowledge reproduced through practices made possible by the framing assumptions of that knowledge." (ibid) Moreover this knowledge is very much based on practice; it influences the body, mind and emotions "in such a way that the ranking, hierarchy and stratification, which ensues, is not just the blind reproduction of a transcendent traditional order, as in feudalism. It produces a new basis for order in the productive worth of individuals, as they are defined by these new disciplinary practices of power." (ibid)

Foucault's conception of power attempts to break decisively with the 'mechanistic' and 'sovereign' view. He envisages a new form of social power which he describes as a 'capillary form' of power which 'reaches into the very grain of individuals'; a 'synaptic regime of power, a regime of its exercise *within* the social body, rather than *from above it.*' This is expressed in the idea of shifting, unstable networks and alliances whose focus is closer to "hegemony as a 'war of manoeuvre', in which points of resistance and fissure are at the forefront." (Clegg 1989 p154-155) Such a network of alliances, resistance and surveillance is dependent upon discourse, by talking, by writing, by faxing, by e-mailing, by radio, by television, by observing by the myriad of ways in which we communicate.

Foucault concentrated upon one aspect of this he chose to call bio-power, which he regarded as power orientated towards "the subjugation of bodies and control of populations in general." He saw bio-power as emerging from the new discourses of medicine and administration, which provided a framework for "the carrying capacity of

new forms of disciplinary power to spread like a contagion from their initial institutional sites." The carriers of "institutional isomorphism in this respect" were primarily the state and the professions. It is these knowledges and practices that they licence which produce the *natural discipline* of the workplace and the wage system. (ibid)

One example of the way in which this developed was the outpouring of talk, concern and writing focusing health but especially on sex. "We have become a singular confessing society...the confession plays a part in justice, medicine, education, family relationships, and love relations, in the most ordinary affairs of everyday life, and in the most solemn rites: one confesses one's crimes, one's sins, one's thoughts and desires, one's illnesses and troubles; one goes about telling, with the greatest precision, whatever is most difficult to tell...one confesses or is forced to confess." (Foucault 1978 p59) The result is the "development of a whole new realm of discourse attending to the definition of what is and what is not 'normal' and what is and what is not available for individuals to do, say, and be." (Clegg 1989 p156-157) These professional discourses increasingly "limit, define and normalize the 'vocabulary of motive which are available in specific sites for making sensible and accountable that which people should do, can do and thus do." In this way bio-power normalizes society through the discursive formations of psychiatry, medicine, social work and so on. The terms of these ways of constituting the normal are "institutionalised and incorporated into everyday life. Our own reflexive gaze takes over the disciplining role as we take on the accounts and vocabularies of meaning and motive which are available to us, while certain other forms of account are marginalized or simply eased out of currency." (ibid)

The process then feeds on itself because what is seen and heard is then documented as a resource for further examination and constraint (? like this thesis). So that the practices of surveillance, elicitation, and documentation constrain behaviour by making it even more thoroughly knowable or known. This new kind of knowledge presupposes new kinds of constraint, which makes actions visible and constrains people from speaking. It is in this sense primarily that Foucault spoke of "power/knowledge". "Finer grained knowledge..offers further possibilities for more intrusive inquiry and disclosure" a

position that potentially asks awkward questions of a thesis such as this. (Rouse 1994 p96)

This process, according to Foucault, underwent yet further development. For example, "biographical unities" like family history of heart disease, cholesterol level or T-cell counts etc produced new kinds of 'human subjects', producing new *kinds* of knowledge along with new objects to know, and eventually new modalities of power." (Rouse 1994 p97) This is reflected in the clinical obsession with normal and normality. If an individual is outside the range of normal (arbitrarily defined) then they are abnormal, or pathological and may need to be normalised. For example, because snoring in fit healthy young men is relatively uncommon, snoring is considered abnormal and operations are available to 'cure it'. Anyone who chooses to adopt a lifestyle that leads to a reduced life expectancy e.g. smoking is regarded as abnormal and attempts are made to normalise them by discouraging smoking. High blood pressure, raised cholesterol levels, mobility, hearing level in children and many other parameters are all subjected to a normalizing process. In this way control is exercised by obtaining a normalising distribution in order to locate an individuals discursive practice within such a field. This then is the practice of "normalizing judgement" that connects political regulation and the "construction of norms as a field of possible knowledge." (Cutting 1994 p4-7)

As a doctor, I recognise that not only am I an instrument of medical discourse that exercises 'disciplinary surveillance' on the population, I am subjected to the same process myself by the institutions of medicine, and society itself. For example, hospitals have for some years been required to introduce 'quality' practices to regulate practice. Morbidity and mortality data is collated and made available to the public domain. From time to time disciplinary hearings are held in the General Medical Council and these often achieve widespread publicity. As I write this a consultant heart surgeon is charged with failing to appreciate that his operative mortality was higher than that of his colleagues.

I inhabit an organisation where epistemic sovereignty (what is perceived as the medical truth) determines what is truth among competing truth claims. Knowledge is constituted as "the unified (or consistently verifiable) network of truths that can be extracted from the network of conflicting statements" (Rouse 1994 p103) allowing truth to stand forth by suppressing error and irrationality. Irrationality in this context are those statements that are not acceptable to the regime that the statement inhabits. One is left asking: Is there a standpoint from which to mount resistance to this 'truth'? It is perhaps this point particularly that separates Lukes' third dimension of power and Foucault's concepts. Lukes' third dimensional description of power represents "the conception of power along sovereign lines." It "embraces the fiction of that supreme power which can enable one to 'get another or others to have the desires you want them to have-that is to secure their compliance by controlling their thoughts and desires'." According to Clegg, Lukes implies an acceptance of the Marxian problematic of 'hegemony' or 'dominant ideology' without accepting the theoretical absolutism which would make this a coherent choice. It is not coherent because of the moral relativism he embraces by accepting a degree of hegemony but maintaining his 'liberal decencies'." (Clegg 1989 p166) Foucault rejects the idea that there is any ground from which to mount a legitimate resistance for the connection, he proposed, between power and knowledge is not just a particular institutional *use* of knowledge as a means to domination. It might be that what counts as a serious and important claim to the truth at one time will not (perhaps cannot) even be entertained as a candidate for truth at another. Truths, according to Foucault, are bound by their historical context and that "what were important shifts in what counted as serious discussion of madness, disease, wealth, language or life, were only evident in historical archives." (Rouse 1994 p93-94) There can be no such thing as a truth independent of its regime, unless it be that of another. It could be argued that liberation in the name of truth could only be the substitution of one power regime for another one. Since one couldn't claim that a succeeding system was going to be any better than the previous one, there is no *justification* for attempting to change it. (ibid)

This has implications for my methodological approach. What justification can I have that an attempt to develop an approach that claims greater *mutuality* is more benign? Indeed, I

could easily argue that an attempt to include personal perspectives of the patient as part of the medical decision making process is resulting in 'greater visibility', greater opportunities for surveillance and discipline and thus incarcerates the patient even more. This certainly raises the question as to whether the shift towards a more co-operative medical approach is nothing more nor less than an extension of surveillance. Foucault approached this problem by suggesting that the approach to adopt is one of mounting resistance. This is not resistance for it's own sake but resistance that is constructive and generative. He argued that a statement, a skill, or a machine by itself cannot count as knowledge but only in the way it connects with "other elements over time does it become (and remain) epistemically significant." (Rouse 1994 p111)These interactions encounter snags which generate conflict with other emerging epitemic practices. Such conflict spurs further investigations, articulations, and technical refinements. Conflict thus becomes the locus for the continuing development and reorganisation of knowledge. Where knowledge does not encounter resistance, "it is likely to lead to little or no further articulation, and to risk becoming isolated and inconsequential."(ibid) Foucault uses the term 'strategies' for the multiple ways in which these elements align or conflict with one another to constitute power relations. Once we recognise the complex and contested dynamics of knowledge production, we might say of knowledge as well as of power that "it is the name that one attributes to a complex strategical situation in a particular society". (Rouse 1994; Jupp & Norris 1993)

How does all of this translate into clinical practice? It suggests that there may be a place for developing resistance to practice. This not only means encouraging patients to ask questions but actually to challenge medical discourse itself. So I began to find myself searching for suitable framing at the beginning of a consultation; "Please feel free to challenge or question any opinions I may express etc" This seemed to be insufficient and I began to pay attention to raising the level of inquiry during the consultation. At the heart of this is the ladder of inference described by Argyris. (Argyris, Putnam, et al. 1985 p58) In making the transition from data to cultural inference to inference imposed by the hearer, inquiry is sought. "What is your reaction to this point?" "Do you agree with me or object to this analysis of the problem?" The practical problem that arose from this

approach when I used it, was that unsuprisingly the consultation time was significantly prolonged. I began to find myself torn between feeling that a problem had been insufficiently explored and stress that came from clinics that overran. After all, in trying to address a power problem from the perspective of knowledge and resistance, I had generated another one by keeping people waiting.

In the interview with Patrick, we partly explore this problem. He suggests that a shorthand way of possibly overcoming this problem from his perspective is to somatise the arguments, the concerns, the resistance, the unexplained pieces of information to a 'gut feeling', what he called 'a sense of confidence'. Many other patients have expressed the same idea. Also in this short section of interview dialogue, I would like the reader to notice that we have reached a stage where he is prepared to mount a challenge to me as a doctor and remind me of an occasion that I "dismissed" a piece of information he had given me. The fact that he was able to do this suggests to me that the dynamics of the interview were such that there was a degree of mutuality in exploring these issues. It suggests that we had at least partly escaped from stereotyped doctor patient behaviour.

P: *That's one factor. This factor is that the doctor is unable to provide this time and thought, due to his work load. It is more likely the patient feels, and I do as a patient, that he has a greater privilege of information than the doctor has*
R: *Mmm mmm.*
P: *because of the fact that I have lived with my condition, I have after all been within the body, the diseased body over the protracted period*
R: *Right.*
P: *and all those details are at my finger tips, they go round my head so often they are at my finger tips. I can remember everything. My doctor can't. That means that uhh the patient has an advantage, it, a minor advantage, but he has an advantage, which he should use uhh uhh to uhh his best interest. Now uhh*
R: *Can, can I ask you, you, you say that's medical information that is*
P: *No, no.*
R: *sometimes ignored? It's not in the conventional sense.*

P: *No, I'm referring to the fact that the doctor gets it with the rounded edges not the sharp edges.*

R: *Ok.*

P: *And the sharp edges being the detail, the subtlety, the little things, which often get missed*

R: *Right.*

(I think this is very important. When a patient raises a point or asks a question, it's asking will contain many motivating elements.

(a) He may be asking a logical question strictly within the framework of the current dialogue.

(b) He may be asking a logical question outside of the current dialogue, relating to matters unknown to his doctor-thought to be too loosely connected perhaps to be worthy of raising with his doctor, or too lengthy to describe, or too complicated to describe

(c) He may be demonstrating an understanding, or lack of understanding, of what may have been previously said.

The point being made here is, in my opinion, there are, in responsive behaviour, clues, which if identified can be more revealing and diagnostically helpful- ***added by P on reading the text)***

P: *or not even raised by the patient but are there if you, you had time to probe by asking questions.*

R: *Do doctors miss those?*

P: *They miss them but the patient doesn't and if the patient is an aware patient*

R: *Yes.*

P: *they're meaningful. If the patient is an unaware patient, they, they're not.*

R: *The, the reason why I asked the question I have done is that I, umm, very much developed a sense that* ***(.)*** *when patients tell you something umm like they instinctively feel like you did that the, the uhh cyst as you called it on your head was a tumour, that whilst that is nothing more or less than a, if you like, a piece of information from, from a patient that is medically unsophisticated*

P: *Yes.*

R: *I think it's, I'm beginning to realise that it's important to regard that as a piece of medical information as important as a blood count or, umm an appearance under a microscope. That is actually telling you something because patients have sensors inside giving information about how they work.*

P: *Well I think that's part of it.*

R: *Is that really that*

P: *I think there is that uhh, that umm instinct because that's what we're talking about really.*

R: *Yes.*

P: *It's, it's an instinctive feeling umm but often if you look at instinct, it is related to subliminal thought which is not easy to, to analyse. Umm uhh I remember the other day I was thinking about why was I so convinced about umm it not being necessary for radiotherapy (coughing) and I couldn't recall why I was so convinced but really it was based upon uhh real facts or real uhh supposition of events I think such as the uhh the umm bad luck factors.*

R: *The statistical construction.*

P: *Yes and, and then eventually and this is umm this is how the mind works as I see it uh all the thought processes were in trauma. They rolled these facts around so many times that eventually you don't have to think about them any more. You carry a sense of conviction but really the conviction is related to the fact that you have uhh uhh analysed all of those, all of that information, all of the subtleties and probabilities if you like uhh and they produce uh uh uh a figure which is your confidence figure and you don't have to relate to it any more*

R: *Mmm.*

P: *because I, I found that that's what I did. Initially I rolled all of the facts around in my head, I thought very deeply about them. I went over these, these probability figures, same, same word again uhh*

R: *I know what you mean.*

P: *but event', but eventually I didn't have to do it anymore because I, I felt a conviction that was founded upon those earlier thoughts.*

R: *So you turned, you turned an intellectual, a series of intellectual processes*

P: *Yes.*

R: *into a feeling.*

P: *Well into a, yes, into a sense of confidence*

R: *Right.*

P: *which had a value to it which was very positive.*

R: *Right.*

P: *Uhh, I, I think you know uhh that you could, you could have a range of* ***(1)*** *senses of confidence ranging from nil to ten*

R: *Yes.*

P: *and I was around the nine and a half.*

R: *Right.* ***(2)*** *Do you look upon it* ***(1)*** *umm I, I think I know what you mean and I, I have umm begun to think that this happens both in myself and in others for quite some time. I look upon it as uhh a dialogue between your umm your sort of intellectual reasoning*

P: *Yes.*

R: *and your gut feeling and, and eventually umm*

P: *I was going to say uhh the gut feeling to me is intellectual reasoning.*

R: *OK.*

P: *Uhh but*

R: *xxx(unintelligible)*

P: *Well I think it's pragmatism. In my case I felt that it was always based upon some sound reasoning, but I am prepared to accept that there are fringes*

R: *Right.*

P: *to, to this whereby the unconscious thought plays a part in making contributions uhh and they may be related to subtleties uhh umm some of them almost long forgotten. Richard I'm going to tell you another thing which you umm you will have long forgotten but I haven't and this one of those subtleties, one of the pointers which you knew about at the time, it was a pointer, it was sitting in my mind somewhere, it was positive and helped this umm sense of confidence at the end of the day and it goes back to the uhh, the illness I had with the uhh diseased uhh uhh testicle. At that time, as part of the uhh uhh*

medication, I was given an antibiotic. Uhh I'll just challenge you to remember that.

R: *No I don't.*

P: *You don't. I wouldn't expect you to.*

R: *Well I wasn't, I wasn't looking after you in that process.*

P: *Umm but you were. I had mentioned it to you.*

R: *Did I?*

P: *Yes. I'd mentioned it to you and uhh your reaction was umm dismissive of it.*

R: *Oops.*

P: *Ok.*

R: *Right.*

P: *Umm.*

R: *You'd been, you'd been given an antibiotic as uhh part of the treatment.*

P: *I'm going to explain it first of all*

R: *Yes.*

P: *and then you'll understand the meaning for this, for me saying this.*

R: *OK.*

(Appendix 2, Patrick)

I might also argue that recognising the consequences of the execution of sovereign power as Foucault suggests result in a position where more rectitude and less absolutism exists in the determination of what others 'real interests' might be. I feel much less obliged to interrogate the truths as perceived by patients until they are forced to align with a conventional medical position. The notion of 'real interests' is no longer subject solely to the arguments of medical discourse. Can I demonstrate this? Not easily, but I have noticed in myself a change of attitude and approach in being comfortable in accepting unconventional solutions which fit within the framework of a patient's beliefs but not necessarily mine. I hope that this is to some extent demonstrable in the transcripts of David and Patrick and is part of the reason to include the complete transcript.

One might argue that disciplinary structure and surveillance only becomes effective when enough communicative 'synaptic' connections are made throughout an organisation so

that sufficient detail and knowledge of what is happening becomes visible. The organisation develops a kind of consciousness. Foucault himself was well aware of the biological parallels with his ideas so I find myself looking for evidence that notions of 'consciousness', the sense that the organisation 'understands' what is appropriate behaviour, appropriate discourse, actually exists. All I can say is that as a doctor practising in a hospital, I do have a sense that the organisation expects me to act in certain ways. This is difficult to demonstrate but as I write this I have just returned from the intensive care unit. I had been contacted at home by phone because of an emergency. When this happens, I am expected to drop whatever I am doing and fully occupy myself with the medical problem. The caller asked if I was on call (which I wasn't) and didn't apologise for breaking into my 'home space' or disturbing my weekend. Once again I then ask myself whether or not I have a standpoint from which to judge the appropriateness of this medical discourse that invades my home? I do not think that such a standpoint exists so I do not know if the 'conscious' wish of the organisation when it pursues and encourages me to pursue a medical discourse is engaged in justified action. We are bound then by the terms of our metaphor to leave certain question unanswerable.

When the phone call from the intensive care unit broke into my 'home space', it was an example of Foucault's third interesting point about space and power.

"Disciplinary space tends to be divided into many sections as there are bodies or elements to be distributed...Its aim was to establish presences and absences, to know where and how to locate individuals, to set up useful communications, to interrupt others, to be able at each moment to supervise the conduct of each individual, to assess it, to judge it, to calculate its qualities or merits. It was a procedure, therefore, aimed at knowing, mastering, and using." (Foucault 1977 p136-137)

Surveillance was often built into the physical structures of institutions that were organised to enhance visibility within them. "Here especially there was a new architecture of power."

(Rouse 1994 p96) Of course this can be seen in the way that departments occupy space in hospitals according to size and influence, in the size of consulting rooms (large for one doctor), waiting rooms (small for large numbers waiting), desk size, chair size, chair height etc. But beyond this is a sense the hospitals are medical spaces, which are influenced and managed by the institutions and the members of that institution. For example, surgeons manage theatre space (I am at liberty to move any device, any instrument and position it in theatre wherever I wish, and occupy the centre of the theatre) and nurses manage ward space. There are still many open wards which lack privacy (the wards on which I work are currently mixed and open), except the 'private' beds which are single. Toilet and washing facilities are semi-public and bedpans are often used on the wards. The nurses station occupies a strategic position of surveillance, surrounded by phone, notes and computers. Valerie comments on this at length.

V:.... the others(nurses), you know, got her undressed, got her strapped up and stuck her in front of the television that close and I said 'that well she really couldn't see' and all those nurses all day, all were behind the desk observing the acute patients just back from the operating you know ward, operating theatre section of the ward. They were behind the desk and they were chatting among themselves and the doctors. They never chatted to anyone else. That's the extreme end of it.

The ward may be visited from time to time by the matron as she 'patrolled' her space.

V: When I first went into hospital, my bed was made 5 times a day. Matron came round to see if you're Ok. There are no matrons and although everybody went weak to their stomachs with some matrons you know, Matron actually checking up was not a bad thing.

But most interesting of all was the connection she made between space and noise; as though one increased ones personal space and personal power, by the use of noise.

V. *All the other doctors, especially the young ones, they're terrified. They've got steel on the heels of their shoes or at least they've mostly got hard shoes. They come across a ward, clack, clack, clack, all the way over. They ignore everybody's eyes. They never meet an eye and they go to the bench and thing, whatever and write it down and then they go and see their patient and it's a kind of total funnel tunnel. It's impersonal and all the rest and you can't, I mean, it, it's been like that for donkeys years and I'm sure it's it's partly in the beginning for doctors a kind of mixture of fear and apprehension and all quite human things as well but it's also to do with esteem and arrogance and the different position in the hierarchy between the nurses and doctors. I don't think it should be perpetuated you know when they come in. I think it should be dealt with and I think all doctors should wear shoes that do not make a terrific noise when they walk across the wards, especially at night.*

R: *What, what does that tell you about the hierarchy for the position of patients in the ward then?*

V: *Oh well patients are there to be seen when the doctor's ready and only then.*

R: *You said 'doctors' Are doctors on top and then nurses? Where do the patients fit into all of this? Underneath, in the middle, on top?*

V: *Well I mean, none of them would be there if it weren't for patients but I don't think they remember that*

R: *Laughter.*

V: *I don't know where they fit. They're there. I suppose they are. I mean they have to be underneath, but it's not a, it's not the same logical thing, as nurses and doctors are all employed for patients.*

R: *I interrupted your train of thought on this. You were talking about doctors going through the ward making noise. That's what prompted me to ask a question. What is walking through a ward noisily at night saying about the environment.*

V: *I don't think, I don't think they think that consciously. I don't think uhh, I think there probably is a lot of apprehension in young doctors first going onto the wards. It must be pretty scary and I also know that quite a lot of you know, the way I mean, if you, you are experiencing seeing terrific pain and suffering or whatever, they would need to protect themselves and build up their own way of coping with it.*

R: *Yes*

V: *and I'm not talking about myself at the moment, and they see it repeatedly all the time and they have to develop a way of dealing with it. They have, I mean, you can't react to that as maybe I would or a patient would every time so they develop different ways of dealing with it I think*

R: *Mmm.*

V: *according to their own personalities. For some it is easier for patients to meet than others.*

R: *But I am suggesting that the organisation may allow a doctor to behave in certain kinds of way because, although you say it's a thinking process for a doctor to walk across the wards noisily at night, the organisation somehow permits that as an acceptable act. Yes, there may be reasons for that as you say.*

V: *Well they're allowed to wear whatever shoes they like. I suppose lace ups or whatever.*

R: *Well I, I, I mean... I meant that there may be reasons why the organisation permits an unfeeling attitude to develop*

V: *Mmm.*

R: *as a protective mechanism but that, that was your suggestion because it would be exhausting to cope with suffering all the time.*

V: *Well I, I was taking that into account.*

R: *Yes, well it's uhh*

(Appendix 3,Valerie)

What is embarrassing about the above description is that I can immediately recognise myself as a young doctor, as that 'terrified' young middle, class, white professional male starting out on the ward.

White Male Power

Vince, writing as a white middle class male, drew attention to the assumptions that underpin behaviour in those who occupy such a privileged position in organisations. He

develops his argument by teasing out the assumptions underpinning critical phenomenon that pervade such organisations. "We are powerful because we are white." (Vince 1996 p143) What appears to be a meritocratic organisation has a structure that permits itself to be constantly recreated. Only those that accept this structure and the values that permeate it can participate. The advantaged position of the white male is reflected in the organisation in that this position gives one the power to develop policies that are "enabling, supportive, defensive, dismissive or blocking." This position may mean that we "refuse to see difference between people" and "define the needs of others through our own needs". (ibid) To realise our will and increase the probability of being able to get what we want from the world, we are also encouraged to be competitive, rational and emotionless; the organisation legitimises this posture. All the time "we maintain that we are powerless to affect change", espousing a sympathy for change but "having a greater investment in non-change". In shoring up this position "we want to be told how to change" adopting a reactive posture and eschewing responsibility. "One of the things that white, middle class men are taught is to believe that we are right and see life as the exercise of power, not as learning how to exercise power. (ibid)

Vince continues by pointing out that this position is 'shackling' as well as enabling. Such socialisation is oppressive in that "what we do is limited by a framework of interests. Managers acquiesce to such demands only because they believe that it is in their interests to do so." No real shift from this position can be entertained until "power issues are perceived, acknowledged and worked on as an integral part of change." In commences by developing a "political sense of ourselves in organisations," more than just a sense of how to manipulate organisational politics. It means integrating "what we are with what we do and acknowledging the emotional nature of work." It means to "unlearn being responsible *for* others instead consider how to act responsibly *with* others." (Vince 1996 p141)

Recall the experience of Valerie, as she sat on the ward awaiting investigations for her problem. The entries in brackets were added by Valerie on reading the text.

V: Yes, it was a young consultant..... This man surely would not be in his position if he were not pretty special. My consultant had spent about ten to fifteen minutes chatting to me, leaning against the wall near the desk, before lunch. During this chat he told me that this procedure was not a problem unless of course (he mimed) you pulled the fluid off the brain too quickly. In which case you might cause a thrombosis - a stroke - or similar. He departed with a friendly grin saying he would 'get one of his boys to do it.'

(I desperately hoped in advance that it would not be the one who came..... he behaved so arrogantly. He looked and dressed as though he might be a slick dealer in the 1980s stock exchange.

He had brought me the consent form for my operation on the night I arrived. He had not expected me to read it and was very impatient when I tried. It was impossible for me to read it with him fidgeting and I capitulated to the system since I knew there would be no alternative, but I asked him what would happen if the operation went wrong (neither my neurologist or surgeon had told me about the risks of brain surgery.) He simply grinned idiotically and said "We'll make it better". I gave up and he produced a fountain pen with red ink in it for me to sign - in the circumstances it looked like blood. He then tried to get an Indian - possibly Sikh - woman to sign and gave the same responses when she could not understand it. She was unhappy and refused until her husband came in later.)

R: Yes.

V: The consultant said, you know, do it slowly. I had a long conversation with him and then suddenly this man comes in and does that.

R: Why did you allow it to happen?

V: Are you saying it's my fault now?

R: No, no, no, not at all. Can I clarify that? I don't think it's your fault.

V: No, it's a joke. I know what you're trying to say but I can only say that most patients, without my, my experience would have been even less likely than I would to have objected.

R: Well what I'm suggesting....

V: But how could I have got round it? You tell me. Apart from just objecting then and making a fuss. You see, every patient thinks if they make a fuss then all the staff are going to lay into them from then on because they don't like people who make a fuss.
R: Yes.
(Appendix 3, Valerie)

Notice how this approach contrasts with the behaviour of another doctor, who was not white, observed by Valerie.

V. ....I said this to Dr X. He had a really, really lovely Indian SHO who you probably know, who used to come into the ward very softly. I noticed by the way that all the staff always called him by his christian name not his surname which they didn't do with most doctors but he would sit on you know, sit on the bed, he would smile at you. If he came into the ward and caught your eye, he'd smile and say 'hello, good morning' or something.
(Appendix 3, Valerie)

Of course these two excerpts have no claim to be typical, indeed I hope they are not, and there are many possible reasons why two individuals engage in contrasting behaviour that may not be dependent upon being white, middle class and male. Nevertheless, Valerie felt her position to be disempowered in the face of someone who appeared to assume a right to operate in a certain way. So that Vince's approach serves to draw attention to yet another hegemony, the hegemony of personal and racial casting, that empirically supports the perceived truth that white, middle class males occupy privileged positions, behave in a privileged manner and expect to do well in organisations. They will find themselves, or make themselves, strategically placed to participate in critical organisational decision-making and reward systems. Marshall also recognises such a form of power. In support of this, attention has recently been drawn to the relatively small number of women and racial minority groups represented in the merit award system, a system of financial reward on the basis of excellence. This hegemony also suggests that female identity should, collectively if not individually, be routinely

regarded as a strategic handicap. "This is not to say that class or gender will function in this way: simply that past sociological observations suggest that it probably will." (Clegg 1989 p198) Certainly, as I look around a hospital, I seem to find evidence everywhere that this is the case. Male doctors working in outpatients are supported by female nurses and secretaries; male surgeons in theatre are surrounded by female nurses and only a few other male support staff.

Feminist scholarship would seem to recognise the hegemony of the privileged position of the white male. What particularly makes feminist research 'feminist' is a "challenge to the scientism that refuses to address the relations between knowledge(and knowledge-generating practices) and power". Feminist research is characterised by a "commitment to a specific, feminist epistemology; that is, a theoretical and political analysis that critiques dominant conceptions of knowledge, and poses questions about the gendered orientation of, and criteria for, knowledge." (Banister, Burman, et al. 1994 p123-124) Given my position as a white middle class male, I find myself asking; Can men do feminist research?

To do this means to be able to genuinely adopt a standpoint that would be totally different from the accumulated experiences of a lifetime as a man and position oneself as a woman. Even the suggestion that this standpoint be considered is in itself a position that may arise from a patriarchal power structure to which one can only state that it may be best to suggest that the question is unanswerable. Alternatively, there may be an argument that men can position themselves "as either willing to learn from, or as participating in, debates in feminist research and may play a part in developing clarity in theorizing the politics of research." (ibid)

Bannister et al suggested three kinds of critique that might help in relation to research topic and process. Firstly, in the identification of distortions and biases in research. "The claim is that models that ignore or devalue women's perspectives or experiences (as most do) are inadequate within their own terms. This is reflected in courses, programmes and documents that add women in to the title e.g.'women and work'. Secondly, to regard

"women's experience as primary in its own terms rather than as a resource to amend existing models." The position of a unitary female experience has been challenged by black and lesbian feminists and that such models do no more than reproduce structures of cultural imperialism and heterosexism within feminist theory."(ibid) The third strategy has been called "feminist relativism, feminist postmodernism, feminist deconstructionism or feminist post-structuralism and all reflect the debate on the inadequacy of all unitary grand theories." All these paradigms challenge the dominant models that have attempted to represent and research women's experiences. (ibid) What unites these three kinds of critique is the idea that gender difference is treated as a strategic intervention to illuminate the field. Such a position frames the way that research interventions are considered. This is because the framing process keeps in mind the possibility of change for such strategic intervention must challenge the status quo; "If you want to know a thing, you must change it." (Mies 1993 p70) In this respect it is significant that it was the interview with Valerie that provided evidence for the position of the white male.

This analysis suggests that it becomes necessary to recognise the implicit assumptions underlying one's position as a white, middle class male. This position cannot and should not be regarded as typical, as central to the perceived truth, around which every other perspective of gender, race and class, must position itself. In previously failing to appreciate this, I overlooked and failed to challenge the fact that the situation has been framed from this one perspective.

The Nature of Expert Knowledge

Doctors as experts in their own illness

What I have been suggesting in my analysis of the clinical encounter is that it may be preferable to adopt a situation that tends towards mutuality, a position in which both parties of doctor and patient would appear to exercise equal influence on the outcome. Is this necessarily desirable? Can I find evidence to challenge this view by exploring a situation where mutuality might presumed to be present.

Since doctors become ill like everyone else, what happens when they become patients? There is evidence in the literature to support the view that an experienced doctor might be aware that the arguments in favour of certain treatments rather than others are not wholly based upon rational argument. (Hamm 1988) Furthermore, the medical discourse through which the power relations of the consultation are conducted, is a discourse that one would expect to be fully understood by the doctor in the position of a patient. Did doctors as patients expect or wish to be 'consumers' in the process and be offered a series of choices and be invited to make a choice? Alternatively did they prefer to accept the recommended treatment option and follow professional advice?

I found myself thinking about this situation when a friend and surgeon, about my own age, unexpectedly found that he had developed a tumour. I followed his progress with concern and interest and whilst talking to my friend's wife on the phone one evening, she mentioned that:

"It was absolutely wonderful for my husband to be looked after by a surgeon who took over. He told us what to do and there was no messing about with this."

I knew the patient to be a well informed, highly competent, academic surgeon and had made the assumption that he and his wife would have liked to have been intimately

involved in deciding treatment. In his particular clinical case I knew that when it came to treatment, there were choices to be made. And yet, here I was listening to his wife describing how wonderful it was to have someone 'take charge'. When I subsequently asked him if he felt the same way he confirmed that he did; he was very pleased to be 'told what to do'. This attitude appeared to contradict to what I was expecting to be the case. Surely, I asked myself, given his academic background, his response would be to make himself familiar with the arguments and decide the appropriate course of action for himself? Whilst this episode didn't constitute evidence about what was happening, it was enough to prompt a line of inquiry into the position of 'doctors as patients'. So when shortly afterwards I met a doctor in a similar situation, I took the opportunity to explore the situation a little more.

I was doing my usual clinic but sitting in with me that day was another junior hospital doctor of about five years experience. One of the patients that day was a young university student, in whom the diagnosis of lymphoma, cancer of the lymph glands in the neck, had just been made. He had come back to the clinic to hear the results of tests that had been done. I explained to him what was wrong, what would happen when treatment was started and what were the chances of a cure. It was obviously a difficult moment and as well as feeling sorry for him, I was conscious of the presence of another experienced doctor in the room watching what was happening. After the patient had left the junior doctor said to me: *"That was quite difficult for me to watch. You see, it is a big issue for me."* Unbeknown to me this doctor had a lymphoma diagnosed when she was 17 years old. She was currently awaiting the results of tests to see if the lymphoma had recurred ten years after her first treatment. The results were expected in about two weeks time and there was a chance that they were going to be positive. I asked her if she would be prepared to tell me how she had decided what treatment to have and where to have it? At the end of the clinic she started to tell me her own story.

At the age of seventeen, in her final A level year, she was found to have a lymphoma. Treatment at her nearest hospital had been very successful and the medical school had agreed to accept her, despite this illness, and she successfully completed her training.

Nine years later she had a series of minor chest infections, and to rule out the possibility of recurrence of the disease, a chest x-ray was performed. This x-ray had been seen in the clinic and was *apparently* clear of any significant disease but a subsequent full report by the radiologist recorded the possibility that a recurrence had occurred. Unfortunately, the report was not returned to the department for action to be taken and lay unnoticed in the x-ray packet. A year later she continued to have further problems and a repeat x-ray was taken and it became clear that a recurrence had occurred. When the doctor took out the x-ray taken one year previously for comparison, the original report by the radiologist was noticed for the first time. She realised she had lost a year of possible treatment and this may have compromised her chances of a cure, she decided to transfer her care to another consultant.

Treatment of recurrent disease in lymphoma is complex and there are quite a few choices to be made. Because of this I was interested to know how these decisions had been made and whether or not she had chosen to become involved in making these choices.

A *"I would leave it entirely up to him. I would undergo any treatment that he would recommend. I didn't question anything."*
Q? *"Wouldn't you go to a library, review the literature and find out all about the various treatments and quiz him on the various options?"*
A *"No, I didn't do that, I trusted him. I completely trusted him."*
Q? *"But hadn't you done this with the first doctor only to be let down?"*
A *"I decided to go back to a doctor that I had known as a medical student at St Bartholomews. I had admired him as a medical student and as a doctor while working there as a House Officer. Everyone knew him to be very good. I trusted that."*

I linked this up with the previous story of my friend and surgeon with cancer. In deciding what to do, they both appeared to have used their organisational knowledge to locate someone whose reputation suggested that they were especially competent. Having found such an individual, they appeared to want to disengage from the clinical decision making process and become entirely dependent upon the advice of this doctor. Other more formal

studies support the idea that physicians as patients express only a slightly higher preference in deciding their own treatment when compared non-medically qualified patients. (Ende J et al, 1989.p23-30; Ende J et al, 1990.p 506-9) However, these studies do not appear to have investigated other strategies that doctors adopt in order to gain appropriate expertise. My limited evidence suggested that doctors might be doing more than simply submitting to the advice of their clinician and using additional strategies to secure the best treatment.

It seems fair to me to assert that knowledge of the competence of individual doctors circulates around hospitals. After all, treatment in the clinic, in theatre and in the intensive care unit is a public process and takes place under the gaze of other healthcare workers. I notice which anaesthetists are meticulous and systematic and who refuse to leave theatre under any circumstances to take phones calls etc. This might explain why it is that some anaesthetists who although might be safe in practice, are avoided by staff when it came to anaesthetics for themselves or a member of their family. Anaesthetists in turn watch me in theatre teaching, handling difficulties, making decisions etc. Similarly, nurses watch me in the clinic taking histories, examining ears etc and although I cannot prove this, no doubt make judgements about competence and thoroughness that enters into the organisation in some way. As a consequence of this, I believe, certain surgeons and physicians become popular choices with hospital staff when they chose someone to undertake their treatment or surgery. This suggests a level of organisational knowledge that determines where advice is sought. Such knowledge appears to exist at the level of professional gossip and is formed and shaped by other professional. Patients would not by and large have access to this professional gossip that is accessible by healthcare staff although from time to time friends ask me who I would recommend. By contrast patients have access to the public face of medicine and are persuaded, if they are persuaded at all, by the 'legitimate power' of the organisation, whose activities are monitored by the 'disciplinary gaze' of the General medical Council and the Royal Colleges. It could be that healthcare staff might feel that that this sense of trust is insufficient possibly because not everyone has the same level of clinical skill and competence.

Although a well argued case has not been made that such events happen in hospital, it seems to me that, at the level of common sense, it would be surprising if it did not. But this process might be suggesting something more interesting. Is it possible that healthcare workers, and doctors in particular, instinctively realise that an experienced clinician makes judgements based on *experiential* knowledge and if obliged to present this in propositional terms, so that consumer choices can be made, becomes handicapped by the process? Is it tacit acknowledgement of the importance of working experientially when functioning as an expert? I do not have sufficient data on the particular experiences of doctors as patients to pursue this further but this argument begins to raise questions about the nature of expertise in two ways.

Firstly, when I say that an expert might utilise *experiential* knowledge in his or her conduct as a professional, I now see this as circumscribed expert knowledge framed by an assumption that *all* relevant medical knowledge can be reduced to a positivist biomedical explanation. What is the status of expert knowledge that is not framed in this way? When a patient says, "I feel ill", should this be regarded as 'expert' knowledge despite the fact that it is not presented in anatomical, physiological or biochemical language?

Secondly, it prompts general questions as to whether expertise from one arena can be appropriately applied to another. More specifically, is the *manner* in which a businessperson, or an engineer, or a production worker makes decisions in business, or engineering or factory matters transferrable to medical problems? Are the patterns that are observed or the recourse to 'gut feel' equivalent? What are the components, if anything, that are common to the decision making process in each of the various disciplines of philology, biology, economics, engineering, everyday living? Foucault argued that philosophical concepts such as *resemblance, representation and man* pervade all the disciplines of a given period " a view that leads him to the notion of an episteme as the system of concepts that defines knowledge for a given intellectual period." (Cutting 1994 p8) If that is the case, patients may also share certain ways of *deciding* what to do that constitutes being defined as expert. This suggests two further questions. Firstly,

patients may access non bio-medical data that ought to be regarded as 'expert' knowledge. Secondly, do they have access to a decision making process that ought to be regarded as 'expert' since we both share a common way, at the 'archaeological' level of Foucault. I cannot answer this but such standpoints began to make me careful to re-evaluate data from patients that is not presented in biomedical formats and prompted me to evaluate the nature of relevant medical data.

Patients as expert in their own illness

There is a group of patients who have experienced an illness for many years and whom it might be argued have truly become expert in at least one way. They understand through experience what it means to have chronic lung disease or chronic liver disease and how such treatment really influence what happens in a way that reading through textbooks cannot give someone. Valerie's (Appendix 3) experience would suggest that in someone with a chronic illness, they can reach a point where they would regard themselves as 'experts' in their own illness and see a need sometimes to impose their will on the situation.

V: I've got a very nice GP who works with me patiently, explains everything and discusses issues of treatment with me. He gives me a fair amount of responsibility in managing my illness and when I need it he will take surgery time to talk. Usually I talk to him on the telephone and as a result I take very little of his time considering how ill I am and I call him out possibly once a year..... .....

Twice, at about ages 14 and 26, I made decisions against my doctors' advice: the first completely instinctive and the second on the basis of my observations of other patients and my own quality of life. These and the decision I yet have to make about transplants I will deal with separately in order not to make this background too long..... .....

I don't think one can underestimate the umm knowledge that anybody with a chronic illness gets of their illness and they certainly have a very, very strong idea of what is going to be good for me and what isn't and it, it quite often is right. It usually, it's, well it's always based on experience obviously because I wouldn't, but it's all usually based on experience also of at least one doctor that I'm in contact with either at the hospital, or my GP who is fairly experienced at the same time. And I sometimes get sent to different doctors or am in a strange hospital if I'm somewhere else and umm and they have a completely different way of dealing with me which actually is, is very distressing

R: Mmm

V: And it's very distressing if a doctor won't listen to you at all about what you know is good for you for instance and there are doctors in all, all hospitals and all surgeries like this and they are usually slaves of either the latest medical text book or the one where they trained. Most doctors keep up to date and they've got a hell of a lot to keep up to date with but I just, I mean there are contradictions now between the Brompton.....I had a short time in hospital in the RUH last year.....

I've never had such clean lungs and it's cleared them out. It clears out at the ends of the, you know, the ends of the alveoli, the sacs that are there, but I don't know what's still down there but it clears it out a lot. And also before this, Frusemide has had an enormous effect on my lungs and, and that's the second story. About six years ago in the winter I had what appeared to be heart failure which my GP put me on Frusemide for, with immediate relief of all symptoms. After two or three months he took me off Frusemide and as soon as I was off, I felt awful again and my lungs were very wet and, and my breathing was worse and I said, 'you know, can I go back on it?' and he said 'yes OK.' But he sent me also to be checked out by the heart consultant at Bristol Royal Infirmary. They couldn't find anything wrong with my heart, there was no evidence of heart failure afterwards but I had all the classic symptoms when I was initially put on Frusemide.

I went up to the Brompton for my next appointment and this doctor just wouldn't listen to me saying that I had been much better and had had fewer infections since being on

Frusemide. He wanted me to go on steroids again and I had really bad side effects from steroids and quite frankly, if I'm on steroids for very long I'd go and throw myself off a bridge. I've been on three times before with the doctors at Brompton. They've all agreed for me to come off and he wants to try it again in larger doses. Umm and I say, 'well I'm actually a lot better on Frusemide. I want to stay on Frusemide through the winter and just see how much my infections are reduced because they certainly seem to be reduced over the summer.' And he said 'well you can stay on this if you like, but you're going on steroids as well.' So umm I said, I said to the consultant, 'if you put me on steroids and I stay on Frusemide and I have a better winter, you're going to say it's because of the steroids and I'm going to say it's because of the Frusemide and you won't know which, which is which, what's had the effect.' Anyway he wasn't going to change his mind so I went back home fairly stressed by this interview. I went to my GP and said 'I wasn't happy with it,' and he concurred and let me stay on Frusemide without the steroids and I did have a much better winter. Went back, asked to see Professor Z, my usual consultant the following spring and said, 'look, I've been better. I've had a better winter, I've only been on Frusemide', and this had been going on by the way over a period of a couple of years by then, which I had been saying I was better on Frusemide. I told him everybody said that it was not doing me any harm, so I could stay on it, but there was no reason at all why it should be doing me any good. Anyway, I saw Professor Z and I told him this story and said that I had been significantly better and had fewer infections and I said 'the other doctor wanted me on steroids' and he knew, he's known for a year, I didn't want to be on steroids. Anyway, half way through this story he started to grin and he said, 'I think there's someone down the corridor who'd like to meet you' and he took me down to one of the Registrars who was doing research into the salts in the lining of the lungs

R: Mmm mm.

V: because the balance of salts in the lungs affects the efficacy of the, the, working and moving phlegm from the lungs in a continuous way. And, I mean, one of the things I found that the Frusemide also did, it's much easier to cough up sputum. I could clear my lungs much more easily and there was much less of it. I went to see him and he was most interesting straight away and said, 'yes you're right, you know, it affects the lining of the

lungs' and of course Professor Z being bright, realised immediately that Frusemide would affect the salt balance in the body, not just in the kidneys or wherever, you know. He made the connection but only after 3 years, you know, the relative arguing, they suddenly decided I was right. Umm and that was from what I felt and, I mean, what I'd observed. But I have to say that the, the registrar doing, who was doing the research is still at the Brompton, did say that it was unusual for patients to observe themselves umm in an objective way accurately. I don't know whether that's right or not. He said most trials, most studies with patients had not reflected what their accurate clinical state was and that's when my other interest comes in, in a sense that maybe doesn't matter if they feel better.
(Appendix 3, Valerie)

Valerie clearly suggests that she is assessing treatment outcomes on the basis of what it felt like as she breathed and coughed. *"I could clear my lungs much more easily and there was much less of it..... and that was from what I felt and, I mean, what I'd observed."* The idea that patients are in the best position to assess themselves, how well their lungs or livers etc work, is hardly groundbreaking, but it is interesting that Valerie remembers that it took three years for her to establish this point. This interview relies upon an accurate recollection of what took place but what is interesting is that the registrar appears to have acknowledged this fact with a caveat that most patients could not be relied upon to assess their clinical state with accuracy. It suggests an unwillingness to surrender the physician's position to know what is best and it may be that patients with chronic illnesses are best positioned to notice this.

Even as I was engaged in trying to take more seriously data provided by patients, I became aware myself of how difficult it is as a doctor to surrender the position that I know best. During an outpatient consultation one day I had a discussion with a well informed journalist, who needed an ear operation. This was complicated by the fact that he had hepatitis C and this carries with it certain risks to both the patient and the doctor. All had seemed to be satisfactory but in retrospect I had seriously misjudged the situation because two weeks after the consultation a letter arrived, part of which I reproduce:

Dear Complaints Co-ordinator: July 15th 1995

On Wednesday July 12 my wife and I attended an out-patients appointment with the ENT consultant Mr R. Canter to discuss the possibility of treating deafness and a discharge in my left ear.....in the course of the consultation, Mr Canter remarked upon the fact that I am a carrier of the hepatitis C virus and attempted to explain some of the problems this might cause in the event of his attempting surgery on my ear (though he did agree, in principle, to operate).....unfortunately, hardly a single word he uttered on the subject has any basis in fact. And where there was fact, there was an astonishing lack of tact....after initially being stunned into silence, I did consider challenging Mr Canter's eccentric views on hepatitis C but as my wife was obviously becoming distressed and we were also in a hurry to attend a parents' evening, I decided the matter was best dealt with by letter at a later stage... "

There then followed a detailed and well-informed criticism of the points I had raised and why they were inappropriately managed by me. This episode raises a number of points. The description that my views on hepatitis are "eccentric" is obviously one that I would contest, but it suggests that his view as a patient, based on his experience and reading of the subject, did not fit with the conventional medical viewpoint that I would have presented to him. We had talked about risk of transmission of hepatitis to other patients via the anaesthetic circuit and to theatre staff via aerosol transmission when bone was drilled away as part of his operation. These points would affect the timing and the length of time under anaesthetic because extra precautions would have to be taken; I felt obliged to let him know about this. Because he had seemed particularly well informed, I had made the assumption that we could talk with one another in a language based on a positivist or post positivist paradigm. The language of the consultation was very medical but in retrospect this may not have been appropriate. This raises questions about how data does or does not make sense when viewed from different paradigms and his paradigmatic position may not have been the positivist one I had assumed it to be. My conceptual model includes a level at which I ask, as a researcher, what paradigmatic position am I holding and in what paradigmatic position I am choosing to communicate. In the consultation I recollect having the kind of conversation about hepatitis with the patient

that I might have with a medical colleague and as a consequence chose a positivist explanatory stance. In retrospect this may not have been correctly framed.

Alternatively, I may have been behaving like the registrar in Valerie's story and experiencing difficulty in surrendering the notion that 'doctor knows best'. There may well have been a dynamic that upon meeting a well informed patient that I was trying to demonstrate to the patient that I was even better informed about his disease; that 'I knew best'. This judgement about his knowledge was made purely on the basis of a biomedical model of the disease. At one level, the theoretical, the biomedical level, I probably was better informed than he was but at another, in the experiential sense, I was not. I could have no real concept whatsoever of what it means to actually have hepatitis C, to undergo a liver transplant and to live with the knowledge that I could transmit this virus to others. Underlying all the talk we had had, was a strategy on my part not to acknowledge his role in any way as 'expert in his own illness' by confining discussion to operative issues and the language of discussion to biomedical language, both discursive practices in which I had greater experience. There were issues for him in which he could have not only made a contribution but played a part as expert. For example, there are decisions to be made about anaesthesia and its potentially detrimental effect on the liver in someone with hepatitis.

[There are a number of alternative inferences that can be made about this event, but no attempt was made to inquire into these at the time. Such complaints are embarrassing and there may have been reasons for not pursuing the matter much further given the way that the consultation was initially so badly misread. But in the context of a thesis, this also represents a moment where inference is badly disconnected from data and the opportunity to explore theory in use as opposed to espoused theory has been missed. Even now I am not sure how I would have handled events differently given that the context was one of complaint as opposed to an episode that provided data to heighten reflexive awareness.]

Earlier on in the thesis, I have reported a study, which found that when surgeons were asked to predict outcome on the basis of 'gut feeling', they could do so with greater

accuracy than a battery of tests. This suggests that, for doctors at least, experiential non-positivist indicators, which may not be accessible to external review, are important in predicting outcome. An argument was made that these should form a legitimate part of the decision making process. Do similar experiential knowledge, 'gut feelings' on the part of the patient predict outcome in this way? I suspect that all doctors have a sense that patients who are positive in their approach to disease, believe in the treatment, do better than those who do not. The whole theory underlying the placebo effect is probably dependent upon this. Little work has been done on the ability of patients to predict outcome but one study attempted to do this. 23,000 people were asked a simple evaluation of health; *"At the present time how would you rate your health ?"* and asked to categorise it into good, indifferent or bad. The answers given were a stronger predictor of death three years later than the objective indicators of physical examination and a battery of tests including blood pressure, blood counts, etc. (Idler EL, Kasl SV. 1991. p55-65). Others are beginning to make the same assertion; "It takes two to tango, and "empowering" patients means recognising their and their children's special expertise on their own bodies, lives, and environments, as well as getting professionals to relinquish 'their monopoly on expert knowledge.'" (Roberts H. 1996, p934)

If the notion that alternative non-biomedical data put forward by the patient has the status of expert knowledge, then I need to consider how to relate this to the biomedical model I hold. If this 'expert' knowledge was explored by further inquiry, then I began to find that this generated data that began to make the decision making process immensely more complex. I began to see this increased complexity as evidence of two things. Firstly, as evidence that reality was being more accurately described, on the basis that no description in life is really that simple. Secondly, much that was subsequently revealed and which became important in deciding what to do appeared to be data that did not fit in well with a positivist definition of what was relevant. I took this as evidence that data from different paradigmatic perspectives was being exposed. This in turn suggested that discursive medical power, which might have been expected to limit opportunities for such data to enter the analysis, was being altered in some way. The assumptive bonds of

positivism were being loosened. This is illustrated by the following story, taken from notes made at the time.

25th May 1992

I recently saw a young teacher of 23, who was troubled with tonsillitis to the point where it was leading to significant time off work. Even between clear cut episodes of illness, she was acting below her best. The arguments for considering tonsillectomy were clearly overwhelming but she was failing to take up this option. She was unable to commit herself to going ahead with the operation despite the fact that she was fully aware of the reasoned arguments in favour and appreciated the very small degree of risk that the procedure would involve. The "voice of reason" was in conflict with her "inner voice" (N Goldberger et al, 1987). *I suggested that she put aside for a moment the 'head' arguments to do with having the operation and concentrated for a moment on what her 'instinct' was telling her. What happened was surprising.*

The first thought/ emotion that came to her was that of her mother who five years previously had died in most distressing circumstances of cancer of the breast. It became clear that she had, as a young girl of fifteen or so, spent a considerable time looking after her. The difficulty she was experiencing in accepting surgery for herself arose from the experience of ' seeing my mother mutilated by surgery' and that the 'thought of having part of my own body removed' was deeply distressing. This distress was impossible to articulate more clearly than this and whilst she recognised the illogical nature of these thoughts and feelings, they were nevertheless real for her.

There remains the problem about what to do with this information and on this occasion I suggested that what had been revealed was important and so;

I suggested that we meet the following week and if she could try and write down some of her ideas around the subject. She did keep the appointment the following week but had not written anything (too much like homework!) and our discussion really didn't get any further. Later that day I received a call from her family doctor and we talked for about

thirty minutes about this patient the problems that the death of her mother had caused her and her family. I had entered this complex world of problems as part of a simple consultation about some seemingly unconnected issue by attention to the dissonance between analytical and intuitive processes, and inviting further inquiry.

It might have possible to have coerced such a patient into proceeding with surgery 'against her better instincts'. As it turned out, when she was given a date for surgery some nine months later, she declined the offer. I believe that she did so because her data (reservations based upon previous experience) had been accorded the status of important medical information pertinent to the outcome and she had been given the opportunity to express this. I had not tried to use Lukes' second dimension power to avoid any discussion of the dissonance between rational and intuitive judgement in case it disturbed the perceived correct clinical decision to proceed to surgery. My suspicion, and it can be no more than suspicion, is that those patients who proceed to surgery 'against this better judgement' and who subsequently experience problems are much more likely to take legal action against their surgeon than those patients whose 'inner voices' have been acknowledged.

On this occasion, and many others I was to find, the 'head arguments' had conflicted with the 'gut feeling'. It is clearly a difficult area, but virtually no work has been undertaken in the medical context that has looked at decision making by the patient when there is a discrepancy between intuitive and rational judgement. As might be expected, it has been suggested that the manner in which information is presented can exercise an important influence on the way that intuitive judgements were retained in the face of evidence that this was entirely inappropriate. (Denes R V 1994.p819) However, such studies might say more about an attitude towards risk, and risk of surgery and the discourse used to explain this, than the problems associated with the interplay between rational and intuitive knowledge.

Whilst thinking about this, I began to look for any discrepancy between rational and intuitive judgement in my practice and ask the patients about it. I found that data

generated in this way often led to interesting areas that had impact upon the decision making process. It seemed to be a powerful way of introducing non-biomedical data into the equation because the purpose behind the question can be construed as an invitation that the consultation process was prepared to enter a paradigm shift. It was also an invitation that data generated in this way would be taken seriously. David, Patrick and Valerie all respond to an invitation to explore this area of knowledge in a way that suggests to them that the phenomenon is real, and I found such reactions typical of those I experienced with other patients in the clinic.

David

D: *I think in making any sort of decision, especially a momentous decision that might affect your life or your death, you draw on all the years of experience that you've had in many, many fields and the decision that you make isn't based upon what you have been told, it's a lifetime's experience... ... ...*

D: *Huhhh, I, I, I think perhaps I don't understand some of it myself. I think there's, we've all got a bit of an inner voice, women call it female intuition, men scoff at it, huhh, but it's there and there was something within me that said "no that's not the route to go, you go.."*

R: *Did you, did you talk to that inner voice at all? Did you find yourself having a, a dialogue with it?*

D: *No.*

R: *You just listened to it.*

D: *I just listened.*

R: *And what do you see, what do you see, where do you see that inner voice coming from?*

D: *And uhh, it, it, it didn't take me very far but um yeah, I, I, huhhh, I think it's true to say that even when I first got the news I'd got cancer and I was having radiotherapy, umm I began to look inwardly a lot more than I had for many many years umm. And cert', certainly within business actually, I, now and again I used to listen to the inner voice, I didn't want to do something*

and say go on, no that's the right way and all... ... ...

R: *Right, I see. I', would you listen to the inner voice if it gave you umm advice that was irrational or contrary to what you might expect to do if you sat and tried to work it out?*

D: *If it was strong enough, yeah.*

R: *Yes. What would you do if there was a conflict? Which would you listen to?*

D: *Mmm, crickey that is difficult. I think I'd go for the inner voice.*

R: *Right.*

D: *I think I've huh gone off the gut for a great percentage of my life you know, you, you, you look at something and you think is it right, is it wrong, oh crickey, can't make a decision. The first thought is yes it was right, let's go for it. And it, it ,it ,it works the majority of the time I think.*

(Appendix 1, David)

Patrick

P: Many discussions on the subject of probability of recurrence arose or relating to it. There was the assumption that it was indeed an independent separate umm cancer but I won't go into that at this stage.

R: May, may I explore that with you?

P: Yes by all means.

R: I, I know your background is mathematical and so if we had quite a discussion about probability and I like the way you've handled it umm I mean I can see what you've done but at the same time you use the word "feel right" quite a lot

P: Yes.

R: so it seemed to me that you used, and I don't want to put words into your mouth but I get a sense that you are using the, these intellectual statistical mathematical arguments to, and, and you have trouble getting data but you've used this until you've got a solution that felt right.

P: Yes.

R: Is that right?

P: That's right.

R: Until you were happy?

P: Well I, yes I was, I, I was uncomfortable uhh I couldn't live with the idea of opposing my doctors (.) who were adamant about it being uhh an independence uhh generation of new, a new cancer uhh and in confronting that with umm uh a rather umm broad vague feel factor..... .....

(Always in my mind were the dire consequences of being wrong, in spite of my firm conviction that this was not a new cancer and, further, my immune system was capable, as it had been for some six years, of preventing further secondary tumours forming.

As I stated earlier my confidence was private and within me rather than confrontational. Before becoming confrontational it was necessary for me to have the opportunity to explain the full case history and present with it my own logical conclusions.

*Regretable, Dr B was not prepared to spend his time listening and as a result I continued to carry my conviction and my worries within myself –***note added by P on reading the text)**

R: You are saying so many interesting things I have trouble keeping them all in my mind, a lot of things I want to ask you but umm and this doesn't directly follow from what you've just said, it just goes back a couple of minutes to a moment when you said you felt powerless umm, in fact, umm to, to do what you felt to be the right thing and (1) I get a sense that what you needed to do was translate the medical knowledge, the information you're getting from the radiotherapy and the general surgeon whom you saw into, into a kind of language that you understood, seemed to be able to make an intuitive decision

P: Yes.

R: that you felt comfortable

P: Yes.

R: with.

P: Yes, well that's,

R: A method of empowering yourself

P: Well yes indeed and I regret very much not asking more questions but umm this is another weakness in, in a doctor patient relationship, particularly with cancer I think.

R: Right.

(Appendix 2, Patrick)

Valerie

R: Where, where, where is the source of your certainty about what's good for you? Where does that come from? You said experience?

V: Well it comes down to gut in the end. It's gut reaction based on experience and umm weighing up the odds umm and the choice to have at the time. Further – it is gut reaction based on a lot of experiences, of feeling really ill from medication.

R: Ok that's interesting. When you take, take that, how do you, how do you get it into the equation?

V: That's an interesting one because that's what I've got to do about the transplant in the end. I have a friend whose daughter, who's one of my very, very good friends and who's been great support to me for some years her daughter is a councillor with London Underground. So when I went up to London to be assessed for the transplant, I actually, I asked her if she'd come and see me and I said 'how do you decide between two things that seem as bad as each other? Because I mean the time that Professor Z was giving me, not that I realised this then, and the kind of death he's described, is not that significantly better than the transplant except that of course it's much less invasive. But basically I asked her 'how do you decide between the two things, neither of which is very attractive?' And umm she came down in the end to something that .....

R: She said?

V: to obtain all the information you can about both, you know, both treatments.

R: Yes.

V: and the consequences of, consequences of the treatment and think them over for a time and my gut reaction would come up. That always happens with me. Somehow, you, you begin to know exactly what you want to do and you then start thinking of the reasons

why. I mean there's a, I mean it's very instinctive thing or intuitive thing I mean I'm quite intuitive about most decisions I make about things anyway. Anyone who thinks like that makes decisions fairly quickly usually and then has to substantiate the reasons why.
R: But you...so once you, once you collect the information, you allow an intuitive decision to develop? Once you've developed that intuitive gut feeling decision, you then construct an explanation based on the evidence you have collected?
V: That's not quite right, you, no, I'm not closed at that point. It usually turns out to be the right decision. You then say, 'well Ok, well why, why have I made that decision? Why does that seem to be the one I want?' and you look at it again and that time the logic falls into place but also at that point I will still at any time listen to further arguments from doctors because my construction might not be right. Or something may have happened to change things.
(Appendix 3, Valerie)

Furthermore, when rational and intuitive judgements were in harmony with one another, I obtained the sense that this represented a weak measure of validity. These experiences gradually led to the idea of the third decision making model.

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator
Type 3	Observer/researcher	Observer/researcher/participator

This third framework model reintroduces the idea that the doctor is also a researcher into the most appropriate decision. Highlighting any discrepancy between intuitive and rational judgement becomes a point whereby it becomes possible to explore the relationship between the judgements suggested by the positivist solution and the judgements suggested by the intuitive perspective of the patient. Allowing these viewpoints to co-exists means that I am choosing to practice as a constructivist but as a

researcher (theory behind the theory behind the data) I have retained an awareness of the paradigm position that I have chosen to adopt at that moment.

How was this translated into actual clinical practice? I began to systematically pay attention to the notion that opinions based on inner 'gut feelings' were a legitimate input into the medical decision making process. This was made explicit by clearly stating, at some point in the consultation, that this was the case. Furthermore it was not necessary to make a decision about what to do straight away. It may be helpful to ruminate over what had been said, to carefully weigh up the arguments, before coming to a any decision. This process may take some time and might involve a number of consultations. At one level, this invitation is paying due regard to a principal of participative action inquiry models with a number of cycles of action and reflection on the part of the doctor and patient. Others may also be participants but the degree to which other members of the group, other doctors, relatives and friends of the patient, truly engaged in inquiry depended upon how close they were to the patient, how interested they were in the problem, how much time they could spend talking about the problem and a whole host of other factors. Such a model is diagrammatically depicted in **Figure 6.**

Whatever the problems discussed in generating a consultation style that approaches mutuality, it has been assumed to date that the patient is an adult. About forty percent of the patients I see are children and developing a participative approach in which they feel free to 'research' their own health, disease and treatment options might present special problems. Naturally I wondered whether it would be appropriate to try and adopt the same approach with children in my clinical practice. Could some of these ideas, some of these frameworks of decision making, be successfully employed with younger patients?

Children as experts in their own illness

When children come to the clinic, most of the time seems to be spent talking to the parents and the children themselves mostly seem to listen. I remain aware that they are

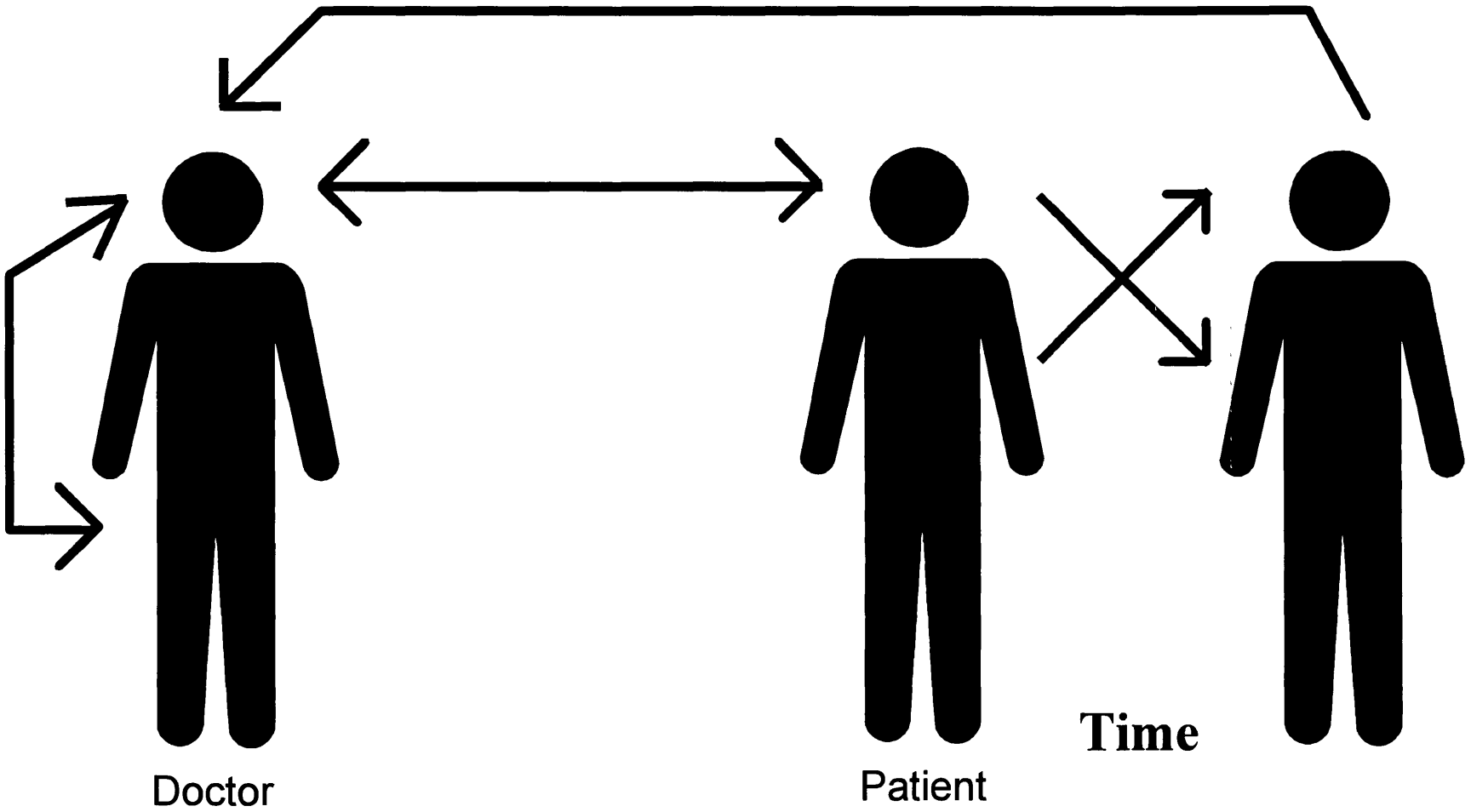


Figure 6. Type 3 The Patient as Researcher

This model suggests that intuitive as well as rational judgement play and important part in the decision making process. Sometimes it is necessary to 'research' any discrepancy between the two.

listening and therefore choose my language carefully in the hope that the children understand what is happening. Part of the time is then spent examining them and in older children some time might be spent in explaining to them what happens when they come to hospital. Prior to starting this research, I would not generally have considered involving children in any other way, certainly not below the age of twelve or so, in any of the decision making process.

Because I was married to a solicitor, I was made aware that the law with respect to children rights was changing. The Convention on the Rights of the Child was adopted by the General assembly of the United Nations on the 20th November1989. Article 12 (i) states that parties "shall assure to the child who is capable of forming his or her own views to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." In 1991 the Children's Act came into force in the UK and in the Autumn of 1991 the Government ratified the United Nations Convention on the Rights of the Child. (HMSO, 1991). These Acts recognised in law that children and young people can make informed decisions but more importantly it implied that if they were not as fully involved as possible in the decision making process, it might be unlawful.

I started cautiously by changing my approach towards young adolescents aged twelve to sixteen. This is a difficult age group because they are perfectly capable of understanding all the issues involved but until the age of sixteen are 'technically' not responsible for treatment decisions as the law stands in England. This is reflected in the consent form which until the child is sixteen is signed by the parent or guardian. I had never felt really comfortable with this and would always ask such children whether or not they understood what was being discussed and if agreed with the decision before the consent form was actually signed. I began to appreciate that this approach might make it difficult for anyone, let alone a child, to really change what was taking place. All the discussion had already taken place between the parents and myself, time was getting short, and there would be other patients waiting to be seen. In considering this, I began to change my practice and started the consultation by saying to the patient something like:

"You have come today to discuss whether or not it would be appropriate to remove your tonsils. Can I say right at the beginning that the decision to do this operation is one in my opinion can only be made by you? I am not going to make it for you, neither is your mum or dad, or your school teacher, although they may help you. It is a decision only you can make for yourself. Also you don't have to decide today, but if you do you can change your mind at a later date."

At this stage in the research, I was explicitly in my own mind using the simple exploratory tool described by Schon of exploration, move testing, hypothesis testing, and evaluation of outcomes. Outcomes were classified in terms of desirable or undesirable outcomes, each of which were regarded as surprising or unsurprising. (Schon. 1983, p153) Given this methodology, what was to be my *move test* to test the *hypothesis* that they were capable to a useful extent of handling the issues involved?

I saw the change in framing the consultation as my *move* test. The perceived *outcome* was that they seemed to visibly relax and responded well to the idea that they could have an apparent input into the decision making process. At the end of the consultation, I would attempt to validate the inference that they were more comfortable by asking them if they minded being involved in this way. The response was usually, but not always, that this change in approach was found to be helpful. This outcome was perceived as a *desirable consequences* that came as *no surprise.* I gradually started to adopt the same style with younger children, ten, nine, eight and then seven years old. This approach has some support from a study on the ability of children to handle and analyse information in determining their own treatment.

"Overall, 14-year-olds did not differ from adults. 9-year-olds appeared less competent than adults with respect to their ability to reason about and understand the treatment information provided in the dilemmas. However, they did not differ from older subjects in their expression of reasonable preferences regarding treatment. It is concluded that the findings do not support the denial of the right of self-determination to adolescents in health-care situations on the basis of a presumption of incapacity. Further, children as

young as 9 appear able to participate meaningfully in personal health-care decision making."
(Weithorn L. 1982. p1589)

I began to notice that if the ages of children fell below age seven or eight, then this approach sometimes produced *undesirable* consequences and they appeared to become overwhelmed by the attention. In children, who were eight years or so and older some *desirable* and *surprising* consequences arose. It should be remembered that a discussion about surgery has to include a discussion on complications and risks and these would ordinarily have been discussed, usually in coded euphemistic language, with the parent. If I was going to truly involve children in decisions about treatment then these risks, including death, needed to be addressed with them as well. I developed methods of doing this in a way that I saw as sensitive and appropriate. Discussing the possibility of dying during surgery with an eight year old may come as a surprise to the reader of this work but in doing so two features became clear. Firstly, the fear of dying during an operation is a common worry among children. This natural feeling could have been enhanced by parental attitudes or even the language of anaesthesia, which with euphemisms like 'going to sleep' are identical to terms used to describe the death of grandma or the dog. Secondly, not a single child, with whom I addressed these issues, seemed to become alarmed at the opportunity to talk about risks and complications of surgery. Sometimes parents might express surprise as the conversation started to move towards such topics but they appeared to be reassured as they saw how well their children coped. Does this kind of involvement represent genuine empowerment? How could my sense that these children were genuinely involved in their decision making be validated? How real, how genuine was this involvement by young children in their decision making? How could I find evidence to counter the claim that this did not represent genuine empowerment?

One day I had the opportunity to find out when I met 'Hannah'. She was eleven years old and had with some reluctance decided that she would like to go ahead with an operation on her ears. I could see that she was very frightened at the idea of surgery but because the problem was potentially serious I was making it fairly plain (choosing what I saw as an

appropriate positivist stance) that there were strong arguments in favour of having surgery. She had agreed to go ahead. She came into hospital a few weeks later and all seemed well until she came into the anaesthetic room. As she was being wheeled in on the trolley, she appeared to lose her nerve and started crying. She then said that she had changed her mind and didn't want an operation. This situation not uncommon and the standard reaction is to proceed with the operation and anaesthetise the child against their will. Everyone seems to become a participant in this. The medical staff might see it as a waste of resources if the operation doesn't take place, the anaesthetist might see it as a test of skill putting to sleep a recalcitrant child, the mother or father, having 'got so far' may wish to finish the process. Hannah saw me, decided that I was not to be trusted, and turning to her mother cried out; *"Mummy, don't let them do this to me !"*

There is a much about an anaesthetic that feels like an execution (or sacrifice). As she looked at me, I suddenly saw the situation in terms of the power both she had and I could exercise in this situation. According to Lukes there were three alternatives. Would I exercise first dimension power and force her to have the operation? Could she exercise second dimension power and prevent the process from proceeding by shouting and screaming and so prevent any real discussion? Could she be persuaded by the exercise of third dimension power to proceed with the operation after becoming convinced that it was in her interests to proceed? Was I going to be true to my description and belief she was genuinely participating in the decision and could exercise discretion? Would the whole ceremony of surgery, once started, now proceed in an unstoppable way? Would the situation be similar to Valerie's as she sat on the ward having a brain cyst aspirated against her better judgement?

Up to now my practice in a situation like this would probably have been to go ahead with surgery but on this occasion such an event challenged my espoused theory that she was able to exercise true participation in what was happening. If my theory in action was to retain control then I would continue the operation despite her opposition. If my theory in action was aligned with my espoused theory, then surgery should be abandoned for the moment. In this respect action had served as a means whereby theory in action could be

explored. Given this analysis my reaction was to say; "that's OK Hannah. We won't do your operation, but will you come and see me in the clinic next week and we can talk about it again?"

Hannah was understandably relieved. The person most annoyed by this was her mother, who didn't say anything but I got a strong sense that she was embarrassed by her daughter's reaction and annoyed that the operation had been cancelled at the last minute. Perhaps, I had not appreciated the emotional turmoil she had been through to get her child to the operating theatre. I explained that from my point of view that, having gained her daughter's confidence, I couldn't let her down in this way. She had a problem that might well require more surgery in the future and I thought that I would be creating problems for myself if I started off our relationship like this.

We met next week. Hannah was embarrassed, apologised for her behaviour and after we had carefully gone through with her once more the reasons for surgery said that she would like to go ahead. Such a position could represent a description of third dimensional power in which I create the illusion of choice but still define 'best interests'. To challenge this, I finished by saying that if she changed her mind at the last minute again, then that was still acceptable. Needless to say the surgery went ahead well, there was no repetition of the anaesthetic room incident and Hannah has had a number of operations since, without apparent difficulty. This was an *unsurprising* and *desirable* consequence in relation to intention. There are issues here of trust as well as power. It could be argued that my strategy was one to maintain trust so that greater power over Hannah could be exercised in the future. It is a difficult argument to counter, after all what would I have done if she had subsequently refused surgery, which I had perceived as important and in her best interests. Nevertheless, I would argue that Hannah had retained control over medical process by exercising her veto over surgery, a position I has encouraged her to adopt, and this represents the first stage in empowerment.

I frequently tell the story of Hannah to other children as an example of how it is possible for them to influence what happens to them. Surprisingly, this particular incident has only

happened once in this age group, so perhaps by telling the story of Hannah to illustrate that empowerment of a sort is possible, my position is seen as authentic. As for Hannah, I suspect that I have set a pattern for the kind of interaction she will have with other doctors for the rest of her life. I have no evidence for this other than the fact that patients often describe similar experiences to this as important in setting up attitudes towards treatments, surgery and doctors that remain entrenched for life. Valerie describes an experience as a young girl, about Hannah's age, and how resisting treatment, albeit in a different context, on this occasion was important in terms of feeling empowered.

V: We moved when I was 10 years old and my mother was investigated very quickly and it turned out she'd got fatal stomach cancer which had gone on for too far too long to do anything about. And when she died I was put in hospital and by then I'd got bronchiectasis as I said, but from then on I did get regular hospital treatment and when I was 14, I was, I was still taking Franol, which was a white tablet. And one day on a visit to the clinic I was given another white tablet to take, a small one, and was told that I'd got to take it regularly. It was most important I should take it at the same time each day and nothing more than that, they told me nothing about it and there was no reason or precedent that would make me refuse it. And I was, you know, frozen. I would not take that tablet and I didn't know why. I went back home and my father had not been unable make me. My aunt also visited but I didn't take that tablet. I don't know why. I went back to the clinic, he questioned me very kindly, over some period of time. I don't know why I wouldn't take that tablet but I wouldn't. It was Prednisolone, which I realised much later that had I gone on it permanently then, I would have been dead long ago.
(Appendix 3, Valerie)

I am aware that such an action on my part may be seen as an arbitrary 'frame experiment' that fails to take into account the complex relationship that parents might have with their children in determining treatment. This area has been the subject of very little research but one study of children undergoing orthopaedic surgery seemed to find that children themselves were more dependant upon their parents in the decision making process than

a control group of normal schoolchildren would expect (Alderson P. 1992. p81-95). However, this simple child/ parent relationship appears to be complicated by a response determined by age and the presence of a third party. "It was found that when the adult directed the children as to which choice alternative to choose, all children (both grades and both sexes) preferred that alternative advocated by the adult. When however, the adult's influence attempt was followed by another adult's stating that the child should choose whatever he/she wanted, first graders displayed oppositional behaviour (preferring the alternative not urged by the first adult), while fifth graders continued to comply with the first adult's influence. These results suggested that oppositional behaviour in first grade children may occur as a function of conflict between adults regarding adult control over the child." (Brehm S. 1977. p31)

There has also some evidence suggesting a relationship between authority on the part of the parent and ability of children, especially daughters in making a decision. "Results suggest that parental authority characterized by stern inflexibility and overcontrol has the greatest influence on daughters who develop chronic indecision tendencies." (Ferrari, J.R. 1993. p963) This may have reflected modelling on the part of the girl because "there was a relationship between mothers' decision-making competence and the competence of young female adolescents."
(Brown J. 1991. p363)

An alternative approach has been considered by exploring the idea of 'best interests' as determined by the patient, parents and gatekeepers, which would include general practitioners and specialists. Instead of one person (myself) determining 'best interests', this activity is seen as a collective decision of interested parties. "Ethically responsible team behaviour includes: weighing risks and benefits of proposed interventions; promoting discussion with families and patients to identify "best interests; ' monitoring outcomes.'" (Mouradian W. 1995. p510) This approach assumes that coherence can be reached in terms of defining 'best interests' by all parties. What would be the approach when difference existed between the best course of action perceived by the parent and the child? Instead of overriding the wishes of the child, this difference was highlighted and to

explore the reasons why this should be so. For example, a child with a long history of tonsillitis might well have reached a point where they were so used to the tonsillitis that for them this was 'normal'. There was no perceived need for surgery. Parents might see it differently. Each attack of tonsillitis was a disruption to the whole family; parents might have to take time off work, would be up at night looking after them etc. The parent and the child would have a completely different perspective as to what need to be done. The 'best interests' of the child and the 'best interest' of the family would be in conflict (Schoeman, F. 1985. p45). Put like this, the perceived difference in 'best interests' could be seen as a difference based upon different perspectives.

I became aware that a more complex situation might sometimes arise when one parent was keen to proceed with surgery and the other was not. A common example would be when the child has recurrent tonsillitis or a significant hearing loss leading to difficulties in language development. In such a situation it often seems that both parents will have taken trouble to appear with their children in outpatients. At the risk of generalising too much, it seems to me that it is generally the mother is keen on some kind of surgery and the father not. What might be happening here?

First of all I get a sense that it has much to do with different perspectives on the problem and here I enter the realm of conjecture for a moment. It is still commonly the mother who will have to face the daily consequences of the clinical problem. They will be looking after an ill child during the day, be up at night more often, and generally coping with the disruption generated by the problem. The father might be more distant from the problem and will be less aware of any difficulties other than indirectly through his partner. When such a difference between the parents does exist and I draw attention to this, it is common for the mother to say: "You're never really there to see what happens!" Secondly, I also get a sense that the father particularly wants to see the surgeon, see the hospital, see the set-up, before giving his permission to proceed with surgery. He wants to judge the organisational competence and the professional competence. It might even go further than this. Sometimes I get a sense that the problem with fathers is much deeper than this. It is a feeling that their children have become a 'ritualistic' part of the greater

healthcare organisation. Healthcare organisations need patients to make them work, to justify their existence, to justify the existence of those who work in them, to be the research subjects to satisfy the curiosity of the 'scientists' who work in them, to make the money go round. I believe this has become much more of an issue since the latest internal market reorganisation in which money 'follows' patients. Articulating these ideas is not easy for either the surgeon or the parent. Any parent with such thoughts might have difficulty making these views known without appearing offensive. As a consequence it is hard to test such conjecture with further inquiry in a busy clinic and it may be necessary to resort to alternative methodologies by others rather than action inquiry on the part of the surgeon involved.

With experiences like this, I changed my practice and began to develop a reluctance to proceed until I could see that there was congruence between these two views; the position of the child and the position of the parents. Resolution of these differing points of view was usually going to take time and I saw it as important not to be seen to take a decision quickly in contravention of the child's view or one parents view. Of course I have no knowledge of what takes place at home, whether the child or one parent was simply coerced and pressurised into proceeding with surgery, but I hoped that a number of actions on my part would help.

- Refraining from making a decision in outpatients when it was clear the child or one parent was not happy to proceed with surgery.
- Making this point in the presence of everyone.
- Inviting the child to write to me directly if they should have questions or difficulties.
- Offering a further appointment for discussion if necessary.
- Advising children that their best source of advice and help was their parents, who had their best interests at heart.

From these and other conversations, I began slowly to develop a sense that data and inference from the patient, which was previously seen as not part of the biomedical model, ought to be acknowledged as 'expert'. This approach, moving as it does towards a

position of mutuality, still leaves unaddressed the problem of validating this. How reliable is such data and inference from patients, from parents, from children? After all, if I am listening to a history from a parent the original data of the disease process itself is transformed by inference as the child explains it to the parent and by inference as the parent relates it to me. Is it possible to connect such second order inference with data more robustly?

A possible approach is to turn around the principals of action science and to regard such data and such inference as a 'self report' on the part of the patient. The patient is now seen as an action scientist producing a 'self report' Two points of view have been put forward to consider the reliability of such reports. One approach is to conclude that "self reports are decidedly unreliable...individuals tell more than they know, unknowingly distort cues...human beings are unaware of their reasoning processes and are unaware that they are unaware." (Argyris, Putnam, et al. 1985 p242-243) An alternative approach is to take the view that "self reports are reliable commentaries...individuals are the best authority regarding their thought processes, they have access to these processes...they are aware that they are aware...may make mistakes...but if their views can be reconciled with those of the observer's...the reasons can be ascertained." (ibid) Action science takes the view that "both views are accurate but only in certain domains and there is a need to distinguish between espoused theories and theories in use." (ibid) Such self reports should be subject to consistent rules to assist validity. These include asking patients to illustrate inferences with relatively directly observable data so that when they make a claim, they provide the data on which it is based. This means making their reasoning explicit and testing for agreement at each inferential step coupled with an attempt to seek disconfirming data and alternative explanations. To affirm the making of mistakes and to design ongoing experiments to test competing views, if the biomedical explanation offers an alternative course of action. (Argyris, Putnam, et al. 1985 p257-261) Although, there are components of this approach that I accept in type 3 framework for decision making, in which the patient acts as 'researcher' into their own condition, such an approach seems cumbersome. Furthermore, as a researcher, I would take the view that such an approach is guilty of imposing a set of validity criteria, which are circumscribed by a particular set

of paradigmatic assumptions, on the situation. In other words, if patients provide arguments that robustly fulfil *my* set of validity criteria as a critical theorist, then I will chose to believe them

What is being asked here is to understand the rationale behind certain inferences made by patients and find them credible. Such rationale may be founded upon experience that may not be easily accessible to the doctor. Some work has shown that patients usually have a rationale for thinking in certain ways that may seem to the medical practitioner "haphazard, perverse or just plain cussed." It was found that this was often based upon previous experiences of health services and health professionals and identified three groups. These were "those who had experienced past frights, those with current concerns about illness and those with a lack of confidence in healthcare professionals." (Hopton J, Hogg R, McKee I. 1996) At the very least, it seems good practice to acknowledge the existence of these rationales even if one does not immediately accept the concept of 'expert' non-biomedical knowledge. Better still, it would seem better to suspend judgement, hold such data and inference made by the patient lightly, respecting them but at the same time inquiring into them to explore the experiences and assumptions that give rise to this interpretation.

Framework 3

These gradual shifts, from only considering positivist data to one that saw data framed by theory reconfigured the consultation process from one where a doctor was seen as the main protagonist to one where each protagonist was expert in different arenas. Such a view represents a further shift towards a position of mutuality. This led to the development of the final two frameworks for decision making discussed later, but which in broad terms can now begin to be seen in the following manner.

Framework 3 and 4

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator
Type 3	Observer/researcher	Observer/researcher/participator
Type 4	Observer/researcher/participator	Observer/researcher/participator

Type 3 and 4 decision making frameworks make an outpatient consultation more like co-operative inquiry where doctor and patient are accorded more equal status as researcher and participator. It can also be recognised that such a pattern seen in progression from type 1 to type 4, reflects a shift in paradigmatic approach. Type 1, in which there is clear separation of researcher and researched, where the researcher determines what is relevant knowledge and the patient is experimented upon is closely allied to positivist principles. Alternatively, a type 4 model, which claims to seek a position of mutuality, is much closer to a participative inquiry paradigm. This obviously raises the possibility that theory (multi-paradigmatic perspectives as a researcher) has generated data (multi-model decision making models) that is theory dependant. This possibility forms the basis for claiming that, as a researcher, I claim awareness of paradigmatic position even whilst working as a constructivist and is evidence that the three level conceptual model is one that I claim to utilise.

Leadership

The previous sections have indicated the complex relationships between power and knowledge. This meant that I was beginning to see myself in the clinic as a facilitator of different forms of data, with methodologies I perceived as relevant to different situations (frameworks). If I claim to facilitate the process, which I sometimes see as a group process, it suggests that an analysis of leadership would be appropriate. My interest in decision making began by examining the head and neck malignancy clinic and in association with this, the hospital Inquiry Group was established. These two groups presented an opportunity to examine leadership in both these environments.

Early on it became clear that there were issues that were related to leadership, or control, and as part of the process of understanding this, I propose to revisit these diary entries once more. At the previous meeting of the hospital Inquiry Group, a decision had been made to change the physical arrangement of the room by altering the arrangement of the chairs. What follows is the diary entry I made after this clinic and the meeting of the hospital inquiry group that followed.

DIARY

12th December 1990

Head and Neck malignancy clinic. Attendance: SELF, 'R' AND 'T', Consultants; 'H' Radiotherapy Consultant; 'Rd', Consultant in Palliative Care; 'S', Senior Registrar; 'G', Registrar; 'C', 'H' (PART TIME), Senior House Officers; 'M', House Officer; 'J', Medical Student.

We had the usual pre clinic lunch, which I have to admit was a bit more subdued than usual. I put this down to a number of reasons. The principal one was that lunch was being hosted by a pharmaceutical representative who was very new to the job and somewhat nervous but we were also joined that day by two sixteen year old schoolgirls

who were considering a medical career. Much of the usual hospital gossip, which livens up these meetings, was absent.

We rearrange the chairs as we had planned. Immediately two issues emerged. Firstly, 'H' who had not been a party to any of the discussions in the meetings because he hadn't been able to attend them, wonders what is going on. He also mentioned that he had not been asked. He questioned why the change of format in the clinic? At this point I found myself questioning, who owned the clinic and immediately realised that I had always considered Hugh as ***our*** *guest in our clinic. When I had explained about the meetings and the decision that had been reached after the second meeting he, being the good-natured and flexible individual that he is, was happy to co-operate.*

As we sat down, 'R' also immediately questioned the decision and how we had come to make this. This raised the question as to how groups actually come to make a decision that we all feel able to put into practice. A little good humoured banter followed. By now we were all in our seats and it was immediately clear that as the patients entered the room they were to be met by a wall of about 12 to 13 faces sitting in three rows all in white coats except 'R', who was dressed in a suit. The nurse attending the clinic said she thought that it was very intimidating and for some reason found it hysterically funny. After that we all started laughing and there were humorous comments about 'power seats', 'R' dressing differently, in a suit as opposed to white coats, like 'God sitting in the clouds' etc. A straw pole at that time found about one third in favour of the old system and two thirds in favour of the new seating arrangement.

The clinic began. There were only six patients, of whom only one had a really unpleasant and difficult problem. We, at least I, hand this problem over to 'R'. 'R' is very vocal in the clinic and spends part of his time constructing diagrams depicting who is giving and receiving attention. Much of the areas we are exploring in terms of patient comfort are areas where I think he feels that he has special expertise and I for one enjoy what he has to say. When I give him the care of this difficult patient, who is destined to die a most

unpleasant way, I feel very guilty at handing over to 'R' such a difficult management problem.

The seating arrangement is judged a success by some, especially by those who I had perceived as being most in favour of the change at the last monthly meeting. I think they felt responsible that it should work and were unanimous in saying that it had helped them to concentrate. Interestingly enough we all found ourselves asking the patients, especially those who had attended before with the old arrangement when we all stood up, what they thought. The answers weren't consistent. At one time three of us, including myself, sat in the patients seat and felt what it was like. For me it felt very good because I was looking at a group of people that I like very much. We all noticed that you tended not to notice those off centre. Pretty quickly the idea emerged that next time we should position the seats so that when the patient entered the room the first thing he should see was his own empty seat against the wall opposite. The main group should be seated to the side of this chair, therefore partly out of view. The presence of a few empty chairs in the watching gallery should reduce the feeling 'of a sell out show' and of 'observers watching an electric chair'. I look forward to next week's discussion with interest.

DIARY

28th December 1990

3rd meeting of multidisciplinary group. Attendance: 'R', 'Rd', SELF, Consultants; 'S', Senior Registrar; 'G', Registrar; 'C', 'A', Senior House Officers; 'K' House Officer, 'K', Medical Student.

We resumed the discussion by talking about the seating arrangement and how much the effect of sitting down had altered our perception and feelings. 'Too small a room', 'too many chairs' were common observations and typical of how many felt. It soon became clear to me that the discussion was dividing people into two groups ; those who preferred sitting down and those who preferred to be standing. Those who preferred to be standing were on the whole the 'decision makers' and those seated were 'onlookers'. It occurred to me that both of these groups had a common purpose in wishing to disengage from each

other. The 'decision makers' felt conscious of the presence of the 'onlookers' in the management of such a sensitive situation and could distance their impact by getting them to sit and talk amongst themselves. The 'onlookers' could distance themselves from the 'decision makers' by being in a seat which says 'I am an onlooker, I am part of the audience that is here to observe'. I mentioned this point but it was largely ignored so perhaps I have either missed the point or that no-one was prepared to acknowledge the disengagement, in case they may be made to engage more actively.

The discussion centred for a while around seating arrangements; its a little aimless and slightly hard going. Gradually we evolve the idea that it would be better if less people were there and that the SHOs could take turns to attend the clinic. One SHO would be in the clinic, one on the ward and another would be doing an extra clinic in another part of the hospital as there would otherwise be nothing for them to do. 'R' and 'Rd' leave and I am now the only senior member of the department left. I suddenly see my research running into difficulties. Because staff change every six months, it would take three months before all new members of the department had attended a head and neck clinic and these discussion meetings would get off to a slow start. I also mention that they are going to be making a decision on behalf of their successors and they hadn't been consulted. Things then started to rapidly liven up.

Initially my comment was dismissed as silly and it was pointed out to me that many decisions were made on their behalf by their predecessors without their input. This was the system. I then commented that I thought that they as a group found it difficult to organise themselves when they were left to their own devices. There had been numerous examples recently of things going wrong because of this disorganisation, to the point where some of the senior members were getting a bit fed up with them. Perhaps, because they prefer to be organised, they had assumed that their successors would feel the same.

My reasons for embarking on this discussion are perhaps a little complex. The most pertinent was that I was disappointed that after I had stuck my neck out somewhat and given them carte blanche to organise their rotas, working days, holidays etc. with the

result that my colleagues had felt that I was not organising them enough. There was no doubt that the experiment hadn't worked out well. I was certainly learning that it is not good enough to simply indicate to people what the goal is and let them get on with it. Sometimes it may be necessary to indicate how these goals might be achieved. Some fairly animated discussion followed and the only two comments I really remember were:

"How can you ask us to make decisions and object when we do?" and
"Richard, you are too much of an idealist".

'K', the medical student, points out that these comments were only made after my other senior colleagues had left. 'S' collared me half an hour later and said that he had expressed anger with them as a group yesterday because he had spent the afternoon sorting out their work because they had failed to provide sufficient ward cover. He was therefore unable to go to the library to do some research. I reply to him that it seems to me that they have failed to keep their part of the bargain in providing cover and he is quite right in pointing this out. Afterwards I felt a little hurt that to be an idealist was regarded as unacceptable but pleased that they could say it.

As I reread these notes, I notice the control I am exercising. I act as choreographer, moving people here and there, conducting 'straw polls', 'handing' over patients to colleagues as though they belong to me. At the same time I am participating in the clinic, greeting patients, examining them, teaching the trainee staff and finally trying to notice what is happening in the clinic and remember what I should put in my diary. It seems unappealingly egocentric and yet how could my colleagues be so tolerant of this, assuming that they were?

When I reflect on this, I am reminded once more of Randall and Southgate. I cannot consider this group to be wholly creative and might better be considered as an 'intermediate' group, a group composed of creative and destructive forces. These intermediate groups, they claim, tend to demonstrate most clearly the three levels of organising, production and emotional leadership. "A group may have creative leadership

on one level, lack leadership on one level and tend towards destructive leadership on a third." (Randall and Southgate. 1980, p28)

In order to try to identify what was happening they propose asking five questions.

1. On which levels does the group have creative leadership?
2. On which levels does the group have destructive leadership?
3. On which level does the group lack leadership?
4. How can you provide the leadership that the group is lacking?
5. How can you change the destructive leadership towards something more creative?
(Randall and Southgate. 1980. p28)

Although these are useful questions to ask, many of them are impossible to answer from my single perspective with unsubstantiated inference made some time after the event. However, some simple observations can be made. At one level this group was a Head and Neck Clinic engaged in a fairly routine task. It takes about twenty minutes to see each patient and there is a sense, in which each patient examined represents a mini creative cycle described by Randall and Southgate of energising, nurturing, peak and relaxing. The energising and nurturing occur when the history is read out and the treatment options identified. The 'peak' is reached as the patient joins the group to discuss the position and we work to identify the most suitable treatment and the relaxing phase occurs in between each patient. This often includes a moment to wind down, to prepare for the next patient and this point it is common for a little light joking taking place. This particular clinic has been operating in this way for many years, so that at one level this cycle, this ceremony happens almost automatically.

One could argue that consultants provide the production and organising leadership. The patient, as it were, 'belongs' to this consultant because the history usually begins with the opening; "This is Mr So and So's patient ", at which point the consultant will step forward and seem to take control. Also as production and organising leaders, they offer information, prepare for the task, synthesise, draw conclusions and tidy up. Other

members of the group, largely trainees, do not appear to have a recognised task as they watch the consultants in the clinic. Occasionally they might become involved in administrative tasks. Randall and Southgate called this arrangement 'the bureaucrats and the bored.' "Here you find a small leadership group, who do all the work, and a passive membership who do very little....The leadership becomes a group within a group, playing to a passive audience who alternate between boredom, angry explosions and being coerced into doing some work." (Randall and Southgate. 1980, p 29)

However, this clinic has set itself another task. It has the set itself the additional task of being a research group. This is not necessarily a task that would appeal to every member of the group, hence the comments that H made in asking who had decided upon the changes in the seating arrangement. I now begin to see much of the slightly frenetic activity on my part as part of a process of energising this group to become more interested in the research task. If this group is seen as a group with two tasks, that of conducting a clinic and that of engaging in research into clinic process, I seem to have assumed a number of roles. Firstly, as the initiator of the research, I have assumed the role of production, organising and emotional leader of the research group, and secondly leadership roles of one sort or another in the main clinical task of the clinic.

Torbert, in work with students that is in many ways very similar, tried to overcome the problem of multiple tasks by working much more in a role of facilitator. He allocating tasks to various members of the group. In his course "Forcing students to be free" he "asked them to chose a task leader, a process leader and a historian." And "then offered them a model that distinguishes among various ways to make decisions (e.g. unilateral decree, two-person 'handshake', majority vote, explicit consensus)." (Torbert 1991 p152) At the end of each session he asked them to review the decisions they had just made about leadership in the light of these categories. Such an approach separated out the various roles in the group in a way that permitted interpretation to be made from several different viewpoints and triangulation by group decision making in a way that was transparent. In the beginning I had formed the hospital inquiry group with no clear way of distinguishing task, from process, from research and attempted to analyse all three within

the same inquiry group. As the research developed and, with the benefit of hindsight and supervision, stumbled towards a strategy where I attempted to separate out these tasks as predominant activities in each of the various inquiry groups. The University Research Group paid attention to research process. The Hospital Research Group paid attention to the reflective practitioner aspect of the research by creating an environment to explore reflexivity. Finally the Patient/ Doctor group paid attention to positivist task, reflective practitioner and research task. This partial separation of tasks is reflected in the methodology but the model also allowed me to practice some aspects of my practice in each of these different domains and then try and bring it all back again into the clinical arena.

What is also clear in retrospect is the recurring problem of disconnecting data from inference. The feedback obtained from the hospital inquiry group on the clinic was initially perceived as feedback to support hypotheses about the manner in which the clinic was conducted and what might be changed to improve it. In fact, such feedback constituted data on the clinic, my role within it, their role within it as well as data about the hospital inquiry group. Failure to distinguish between data from these different arenas clearly enough meant that inferences were never properly validated. Were the reactions of some members of the group based upon their perspective on the clinic and its problems or generated by participation in an inquiry group about which they may have had misgivings? Because of this failure to properly connect inference with data, the opportunity has been lost to explore leadership with the group, particularly with reference to Torbert's ideas on different leadership styles. In what respect could my style by considered opportunist, diplomatic, achieving or even strategic? I am not sure just how useful trying to classify oneself is but the ideas inherent within the leadership styles are certainly useful to consider. For example, at a " 'strategist' stage a person ceases to take the existing overall structure of social systems for granted as appropriate (or at least as inevitable) and therefore becomes interested in what a normative (a best, a just) structure would be." (Torbert 1991 p51-52) Such a purpose would seem worthwhile, so what are the characteristics that manage such transformations to a more just system? Transformation, according to Torbert, is dependent upon perceiving a sufficiently

complex reality in order to "develop an explicit, unique, theoretical synthesis...that provides greater guidance for action. Alternatively, the gradual recognition that systems effectiveness and justice can require not just a change of actions, but a change of goals, structures and values, leads some to develop a synthetic theory that accounts for and helps to generate transformations of frame in self, organization, or society." (ibid)

My espoused claim is that I am engaged in trying to change a structure to a more just one where power is not unilaterally exercised by consultants. This mutuality includes mutuality with patients and mutuality with trainee medical staff and possibly others. Evidence for this would include setting up a discussion group in which trainees can have the kind of conversations with consultants that I would not have been able to have had as a trainee myself. I believe some diary records would support the nature of this. The body of the thesis would lend some support to the notion that I was trying to do this with patients. In Torbert's view such transforming power "*invites mutuality*- a mutual exercise of power guided by a living awareness of what is currently at stake for the particular systems participating in the transformation." So from my perspective I appear to have gone some way towards substantiating a claim that some transformation has taken place but, as Torbert also warns, "the temptation and danger of the strategist....is that he or she may very well come to rely on a plausible and powerful theory, rather than on continuing efforts of awareness.....to avoid such outcomes (real change in organisational structure)". (Torbert 1991 p57) It is certainly a possibility that this whole exercise represented by this thesis is nothing more than an exercise in creating a plausible and attractive theory to maintain the status quo. Indeed this very statement may be part of that so that it is impossible to break out of this loop of without reference to others unless I choose to be "actively seeking, challenge and contradiction." (ibid)

Evidence that all was not well in this stage of the research is to be found in the way that I had initially tried to empower the trainee staff by disempowering myself. Instead of me organising their rotas and work schedule, they had been encouraged to do these tasks themselves.

"I was disappointed that after I had stuck my neck out somewhat and given them carte blanche to organise their rotas, working days, holidays etc. with the result that my colleagues had felt that I was not organising them enough. There was no doubt that the experiment hadn't worked out well. ... ...
"How can you ask us to make decisions and object when we do?" and
"Richard, you are too much of an idealist".

This was a problem experienced by Torbert as well. "In my own early attempts as an adult at leadership of socially innovative organizations, I exercised power as little as possible in order to empower others. Only upon reflection afterwards did I begin to realize that these situations had required a greater exercise of power (at times unilateral, at times logistical, at times transforming), and that what I had in fact enacted and thus modelled for others was *not* exercising power.... a large proportion of my co-workers tended to assume that I was utterly naive or that I was mysteriously devious and manipulative...my self disempowerment had powerful and negative effects on others." (Torbert 1991 p69) Torbert does not provide data for this assertion but it certainly was one I had sensed myself.

This last point made by 'K' in the diary section is interesting and illustrates a problem I came to recognise in the clinic and in the workplace. *"'K', the medical student, points out that these comments were only made after my other senior colleagues had left."* He was indicating that if you make yourself approachable and create an environment where people, patients and colleagues, can say what they want, some unexpected things happen. Was this in any way reflected in what was happening in the clinic?

I gradually became aware of a change over the following years and it had much to do with the exchange of information and feelings. I have suggested earlier that an ordinary clinic should really be regarded as a group, subject to many of the same processes that take place in groups. In the same way that members of well run groups will pay closer attention to what other members are expressing, listen more carefully, *inquire* more into the meaning of what was being said, the same was beginning to happen to me in the

clinic. I believed that I was encouraging patients to say more clearly, more freely when they really wanted to say something. Evidence for this seem to come from the way that patients were more freely expressing anxieties and feelings around surgery, especially risks. As a consequence, my clinics were taking much longer. This suggests challenging traditional patterns of working where patients see themselves as "traditionally passive, afraid of doing wrong, afraid of being labelled a troublemaker." (Roter DL. Hall JA. 1992. p17).

Of course much of this should be part of a good clinical consultation, but I was experiencing a sense that the formal nature of the boundary, which determined what was exchanged in the way of information, was changing. I had a sense that the structure of the consultation had changed and the medical discourse was starting to include data that was not necessarily bio medical in the positivist sense. For example, I saw a patient recently who firmly believed that air through the right nostril provided oxygen for the right half of the brain and the left nostril did the same for the left part of the brain. This is the teaching of one eastern religion that formed an important part of his particular belief system. This idea makes no sense to me but in a participative clinical style this idea would need to be given recognition. This openness, this less judgmental approach, seems to challenge the traditional role of the doctor and appeared to be welcomed by patients. A line of argument suggesting that if you are 'nicer' then people will talk more easily to you, is hardly ground breaking. What surprised me, was that this perceived open approach resulted in unexpected hostility. Why should this be?

Head and Neck Clinic.
12th Aug. 1992

One moment from the clinic really stands out. I made the comment that if you make yourself 'approachable' as a doctor you had to accept that from time to time patients were inclined to 'heap abuse on you'. They felt free to say what they felt about their predicament. This seemed to ring a cord especially with Hugh who must be one of the

most approachable doctors I know. It may be a price to pay for being approachable but it doesn't make it any easier to accept.

Part of the reason may be insufficient framing of clinical style. If patients were expecting a certain approach, a certain clinical style, and didn't find this, it might leave them uncertain and like the trainees, feel uncertain of what is expected of them. Alternatively I may be misjudging openness as 'hostility'. I had experienced a little of this with Greta at the Hawkwood conference when she had explained that she was able to tell me about her unpleasant experiences in medicine because I appeared to be approachable. I had misinterpreted as hostility. Being able to express one's true feelings as a patient, even if they are hostile, may be evidence of a truly open mutual engagement and as such may be regarded by patients as a hallmark of quality.

How do patients judge quality?

The hospital co-operative inquiry group continued to meet on a regular basis, two to three times a term. The next diary entry was made after a head and neck clinic in February 1992 and provided the impetus for a discussion on quality,.

12th February 1992
Head and Neck malignancy clinic. Attendance: SELF, 'R', 'T', Consultants; 'H' Radiotherapy Consultant; 'Rd', Palliative care Consultant; 'M', Maxillofacial Consultant; 'C', 'H', 'D' Senior House Officers; 'S', House Officer; 'F', Dental Nurse.

This was the first clinic for the new group of SHOs who had started at the beginning of February. A word about them. They all seem rather experienced and have been qualified for a number of years. One of them, 'C' has worked in the department some years ago, before my appointment, as a House Officer. Two of them have just spent a few months returning via the far east after working in Australia.

There are only four patients to see. 'R' is ill and 'T' is away, along with the registrar 'P'. The senior registrar is in theatre sorting out a problem and does not participate at all the whole afternoon. It is a bright sunny day outside and contrasts with the problems we are facing in the clinic. We all sit down on the chairs. Even with the reduced numbers we have today, the row of faces seem formidable. 'H' the radiotherapist is late to arrive and so we have twenty minutes to chat. The small clinic and the small number of people seem like an ideal way to start with the SHOs.

'Rd' starts talking about what he calls 'if only'. What he means by this is the expression used by patients when their doctors has been responsible for a mistake that has threatened their chances of a cure. We admit to experiencing very few patients who say this or use a similar expression. 'Rd' says that in his experience it is fairly common and

often directed at hospital doctors rather than their general practitioners. I suspect that one of the reasons is that any patient in a predicament with their disease is going to be anxious about confronting their potential saviour (?) with anger and will choose to displace it.

The freshness with which 'Rd' speaks makes me think that he has just had an experience with a patient like this earlier on today and I ask him if that is the case. He explains that this is indeed so and I am reminded of the impression I have that people walk into a room carrying their 'baggage' with them. Then one of those odd coincidences happens today.

Our second patient is a lady of about 35 years who unexpectedly found that she had a cancer of the thyroid gland diagnosed and treated about 10 months ago. The relevance to the above lies in the discovery that she had been trying to tell her general practitioner for quite some time previously that there was something wrong, only to have these fears dismissed. Finally when she eventually gets to hospital the surgeon aspirates some fluid from this lump and throws it away without sending it for analysis despite being asked by the patient to do so. He also ignores the fact the lump is still there. Eventually she refers herself back some three months later to be told somewhat brusquely after it was removed, that the lump was malignant. A classic 'if only' story, which we hardly ever hear. She is new to the area and has been referred by her family doctor for continuing care. It is clear to us that there is considerable anger on her part towards doctors, loss of confidence in the system as it has served her. Furthermore we all feel that she has been inadequately treated.

I encourage her to talk about her feelings towards the surgeon and she talks with very little prompting for about fifteen minutes gradually becoming more animated and as 'R' observed afterwards with increasing eye contact with me. At the end she thanks us for being the first group of doctors who have listened to her and she takes her leave with a promise from us that we will do our best to restore her confidence in the system. This has obviously been emotionally draining and I think that we do need a moment to talk about the experience. This doesn't seem to happen and we move on to the next patient.

What makes one patient trust, relate, have clinical confidence in a particular doctor rather than another? These questions must in some way be related to what is the perceived quality of a consultation. Therefore, such a question may be reformulated to ask how do patients judge the quality of a clinical consultation?

The question of quality of a clinical encounter covers many areas. One review looked at 107 published studies examining both organisational factors as well as others in relation to patient satisfaction and ranked them from most to least important in the following manner:

- Humaneness
- Technical Competence
- Outcome
- Facilities
- Continuity
- Access
- Information
- Cost
- Waiting Times:

(Hall JA 1988. p935-9)

Some of these factors are bureaucratic, measurable and have political weighting. Access, waiting times, facilities and cost would fall into this category. They reflect measurable factors that are related to Foucault's disciplinary structures of organisations that concentrate on producing normalising data. Such data is in the positivist paradigm and are concerned with *throughput* and *unit cost.* The remaining ones are really non-measurable, medical and assessed non cognitively by the patient. These measures belong to the qualitative paradigms and it is interesting that they are perceived as by and large more important. Also these variables are not independent of one another and indeed improving performance in one factor might contrive to diminish performance in another. The 'humane and competent' doctor in a practice might, over a period of time, become

swamped by requests to be seen by patients so that access and waiting times become poor. He or she in the USA might control this by cost but in medical practice in the United Kingdom this is not possible. Bureaucratic and political attempts to improve access, waiting times, costs and crude measurements of outcomes may be made at the cost of humaneness and information on the part of the doctor simply because conforming to appointment times introduces severe time constraints on the length of the clinic appointment. For these reasons, it may be quite impossible to achieve high satisfaction scores on all these issues. Patients can recognise the organisational bureaucratic elements of a clinic and judge quality in those but doesn't seem to rank them as important as the non-cognitive elements of quality.

Is courtesy by the doctor perceived as competence by the patient? Apparently not. Simply being a courteous doctor is not enough. Patients perceive a competent doctor as courteous but do not perceive a courteous doctor as competent unless actual competence is portrayed in some way or other. (Willson P. 1982. p1699). One study showed that patients were capable of assessing professional competence despite the absence of any specialist medical knowledge. When independent medical researchers scored a medical record for appropriateness of medical action in the accident and emergency treatment of burns and compared these with patient assessments of competence, they found a good correlation (Linn BS. 1982. p255). Nobody knows how patients make such judgements of technical competence because they would not be expected to make them on the basis of medical knowledge and information but make them they do. Another non cognitive factor that appeared to be especially important was the need for an 'empathetic' approach. "Provision of information needed for decision-making appears to be valued largely within the context of a caring physician-patient relationship. Specific surgeons' behaviors believed to facilitate patient adjustment include expressing empathy, allowing sufficient time for patients to absorb the cancer diagnosis, providing information, and engaging the patient in treatment decision-making." (Roberts C S et al. 1994. p336)

This study reported these findings from a particular set of patients (all women) and a special problem of breast cancer. Whilst everyone would regard an empathetic view as

important, this may not be a generalisable finding for all other medical problems in both sexes. Studies that consider 'empathy' as a parameter outside of these special clinical cases do not seem to have been undertaken. However, common sense tells me that everyone would wish to have a sympathetic physician provided that they were seen as professionally competent. The problem for the doctor is portraying empathy and continuing to do so from one consultation to the next every single day for a working life of forty years. On a practical point this is greatly helped if the doctor actually likes the patient ! (Roter DL, Hall JA. 1992. p138) The consultation then is a trade off between good feelings and obligation.

Examination of a number of variables that characterise a good doctor interview reveal a number of interesting points. Younger doctors were perceived to be better than older because they behaved more competently, both technically and interpersonally, because they "engaged in more non medical talk and to conduct longer visits." (Roter DL et al 1988. p99). This would be in keeping with an audit we conducted ourselves on patient satisfaction within the department, which showed that patients were at least as, and in fact slightly more, satisfied with an opinion from a trainee than from a consultant. Healthier patients were more satisfied patients (Pascoe GC. 1983.p185) although an explanation for this may be that dissatisfied patients are simply dissatisfied people. Patients were considerably more satisfied when continuity was greater (Roter DL et al 1992. p17). If doctors were perceived by their patients to have a "warm personality, used a biomedical model that related to the patients model, had a patient centred interviewing style and were involved in a "true exchange" of information then the consultation was perceived as more satisfactory." (Rosenthal R et al 1975.p679; Stewart M. 1984.p167).

What is the attitude of 'insiders' in the organisation towards quality? For example, does the attitude of patients and doctors when they are patients differ in this respect? From a personal perspective, I would pay little interest in the organisational aspects of quality such as waiting times or cost if I was seeking a medical opinion. This appears to be a widely accepted viewpoint among other doctors when considering treatment for patients and for themselves. "Factors related to the kind and quality of medical care the patient

would receive appear to be most important in the decisions, with a high level of agreement between and among general/family practitioners and general surgeons as to the relative importance of the factors." (Ludke R. 1982. p782) Doctors judge this quality of care by consideration of the five traditional skills of medical care such as "diagnosis and treatment, effective communication with patients, problem solving, lifelong learning, and counselling on medical ethics." and "the doctors value above all the patients' rights and the scientific approach." (Finocchio L J et al. 1995. p1023; Grundstein Amado, R. 1992. p129)

This is an interesting position because it suggests a different paradigmatic perspective on task and process in exercising judgements. It suggests that the paradigm (qualitative) used by patients to judge process quality is at odds with the paradigm used to undertake the task (quantitative according to the perceived medical view). One reason for this may be, on the part of the patient, a lack of familiarity with the indices of quality in the quantitative paradigm and so it becomes difficult to make judgements of quality in this way. An alternative view is that competence in non-cognitive factors such as communication is perceived as evidence of competence in other arenas. This would be in keeping with our everyday experience in that politicians are judged by their effectiveness as communicators although this view may not be sound. Finally, it is possible to argue that such a discrepancy represents tacit acknowledgement that there are important components of the interaction that are not identifiable by quantitative analysis but lend themselves to qualitative judgement.

The end of the hospital inquiry group.

The Hospital Co-operative Inquiry group met from October 1990 until May 1992. In the last six months the meetings met somewhat irregularly and then eventually stopped meeting altogether. There would appear to be at least three reasons for this. Firstly, the inquiry group appeared to me to be making no progress in my understanding of decision making. This was partly due to a naïve expectation on my part, a belief that the inquiry group would continually focus on decision making until a formula of 'rules' of

engagement would emerge and be refined. It was a failure to appreciate that participation in an inquiry group achieves greater understandings and in this way formulates better explanations for social processes. The sense that 'progress' was not being made was reinforced by the fact that the constitution of the group was forever changing. Every six months the trainee staff would change as they moved off to other positions. Secondly, the cessation of the inquiry group represented a stage in my development as a qualitative researcher. I mentioned at the beginning of this section on Reflective Clinical Practice that I identified three stages of development as a qualitative researcher determined by perceived methodological usefulness. These were from co-operative inquiry to supported action inquiry to action science/ inquiry in the clinic. Thirdly, I was beginning to develop a sense that my interest in such an inquiry group was perceived by others in the department as faintly ridiculous. I learnt several years later (1995) that in the latter stages of the inquiry group, certain members had decided to 'set me up' by advancing certain positions to 'see how I would react'. There may be many reasons why this happened and I suggested earlier that one reason was a failure to understand the various issues of process and task that take place as a group develops.

Rather than concentrate on the apparent 'failure' of the group to continue, it seems more meaningful to ask the question; would I attempt a co-operative inquiry approach if I were to explore decision making today? When I look at my research as it is presented in this thesis, I believe that the theoretical explanations have some merit but other explanations are weak. In this respect I see the disconnection of inference from data in the pursuit of explanation to be too great to allow any kind of generalisable statement to be made. I also appreciate that a co-operative inquiry methodology may more rigorously validate propositions by attention to the process of connection data with interpretation. I admit there would be many organisational difficulties in setting up and participating in such a co-operative inquiry. This would be more complicated by the need for involvement of other actors such as nurses and patients, but such a methodology would create opportunities to overcome some of the deficiencies I see in this thesis. I have also developed as a qualitative researcher to the point where I may be able to do justice to the complexity such an inquiry might generate. My reasons for believing in this statement lie

in the similarities I see between co-operative inquiry and the position of mutuality I see in the decision making model represented in framework 4.

Framework 4

The three decision-making frameworks identified so far have a pattern that suggests increasing involvement in terms of participation and research from both the doctor and the patient.

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator
Type 3	Observer/researcher	Observer/researcher/participator

I have so far held back from the idea that the doctor 'participates' within the clinical encounter in the same way as the patient. I recognise that it is hard to shake off the idea of watching, of observing and researching that characterises the role of a doctor in a more technical branch of medicine, such as surgery. The methodology of co-operative inquiry left me wondering if this sense of detachment could be disturbed and the pattern present of increasing involvement of both parties in the above three frameworks suggests the development of a further framework that included such participation.

	Doctor	Patient
Type 1	Observer/researcher	Observer/participator
Type 2	Observer	Observer/researcher/participator
Type 3	Observer/researcher	Observer/researcher/participator
Type 4	Observer/researcher/participator	Observer/researcher/participator

Framework 4 is represented diagrammatically in **Figure 7.**

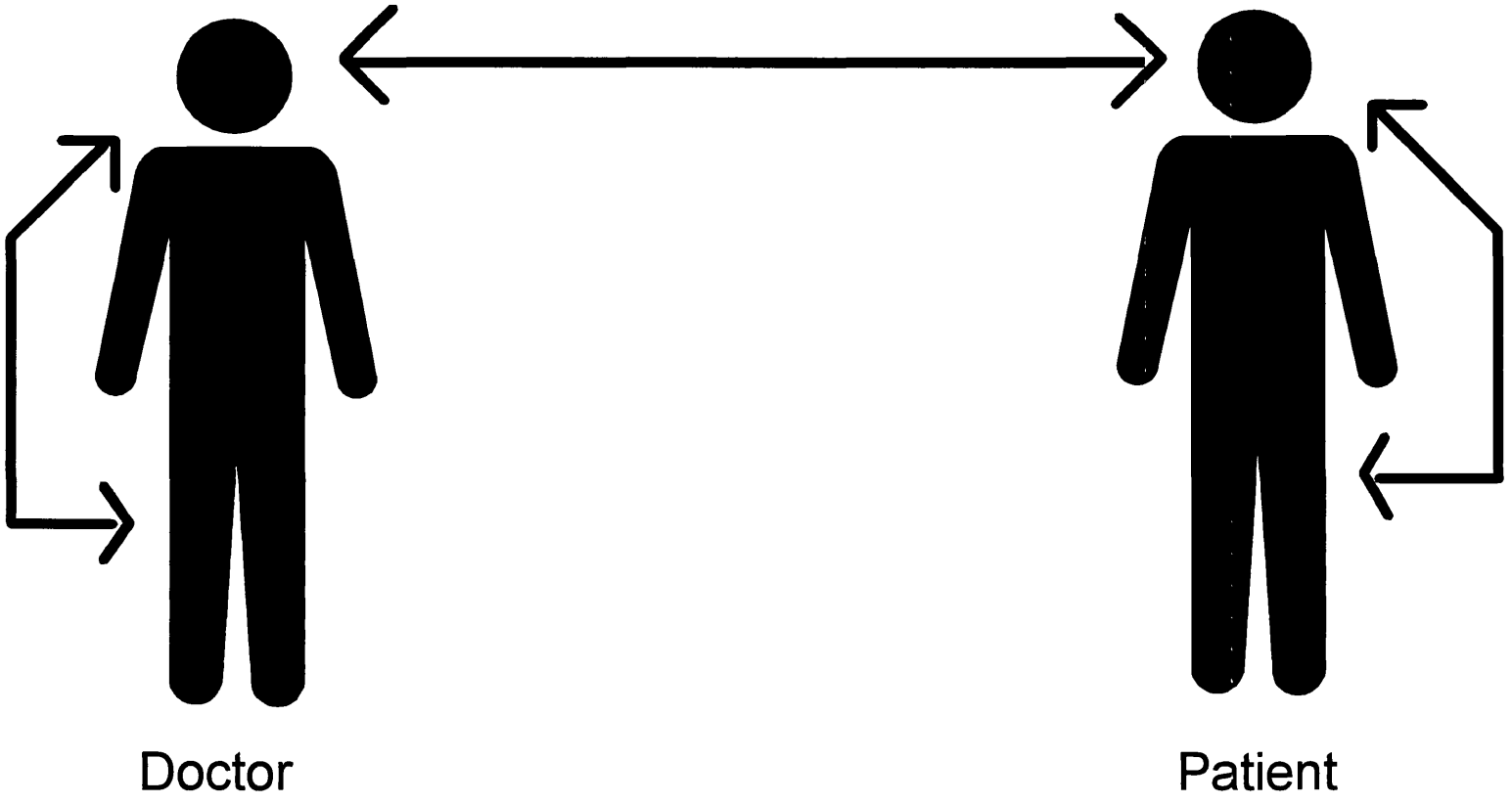


Figure 7 **Type 4 The Patient and the Doctor as Participators and Researchers**

This framework represents a position where the clinical interaction is seeking mutuality. Both the doctor and the patient are perceived as experts, researching explanations as full participants

I am conscious as I write this that what I am about to suggest is tentative and uncertain. I am also conscious that it represents a view of participatory research that espouses complete mutuality but may in reality be nothing of the sort. I can only respond by making the argument that it suggests an area for exploration. Reason has argued that "we can only truly do research *with* persons if we engage with them *as* persons, as co-subjects and thus as co-researchers: hence co-operative inquiry, participatory research, research partnerships and so on." If this viewpoint is to be genuinely upheld then "complete personal engagement, passion and profound risk-taking are central to inquiry, and science and life are not separate." (Reason P. p 9-10. 1994).

Certainly I have the feeling as a doctor that I do not engage in this manner and that the science of medicine is separate from everyday life. No matter what the problem faced by the patient, I remain detached from this problem. I may engage in a professional sense, trying to utilise all the medical knowledge that I possess, but for the moment that is as far as it goes. To date it would seem appropriate to describe my position as observing and researching but not participating. The co-operative inquiry forms of action science force one to ask the question whether or not it is possible to attempt "complete personal engagement, passion and profound risk-taking", and if so what would the level of participation be? If it is possible to adhere to the idea that "science and life are not separate" then how is that gap bridged?

It seems to me that at one level the doctor and the patient will always be separate. This is at the level of the disease itself. If I do not have a tumour, then I can never really experience what having a tumour really means to the patient. Some bizarre attempts have been made to overcome this in the past notably by John Hunter (1728-1793), who in an attempt to demonstrate that gonorrhoea and syphilis are manifestations of a single disease, inoculated himself and contracted syphilis. I am obviously not suggesting participation in this manner but more a loosening of the sense of detachment that I experience as a doctor so that such participation changes me not just in terms of professional practice but in terms of, for example, how I view life. I am suggesting a

degree of involvement, some degree of participation in the problem that would close this "gap between science and everyday life" a little.

If this was attempted, I had a sense that two interesting things began to happen. Firstly, the disease, the medical problem, becomes a vehicle around which other everyday meanings of life may be evaluated. This is not just a romantic view and may have been what Decartes meant by the phrase "by our illness, we know ourselves." The difference here is that it may be possible for a doctor, or any other carer, to be included in the process of acquiring knowledge. Secondly, it once again may become possible as a doctor to exercise unilateral informational power once more because if mutuality is a reality, the patient should feel empowered to accept as much or as little from me as they wish.

It is hard to know if such changes happen at all but I do notice that each week the British Medical Journal has a weekly section that invites contributions entitled "A patient that changed my life." Usually these contributions emphasise a change in professional practice, a different way of treating patients but from time to time they receive contributions that illustrate how a patient changed the life and attitude of the doctor. I do not know whether I have genuinely experienced such mutuality but I certainly experienced a glimpse of this when I was involved with David. The story has been outlined already but I will briefly summarise the situation.

He was forty years old and presented with cancer of the ethmoid sinuses, which are a group of sinuses located between the eyes and extending backwards to about the middle of the head. A cancer here presents a serious problem for treatment. The initial treatment offered (the doctor as healer) was fairly straightforward. This was a course of radiotherapy, which consisted of daily visits to the centre, each one lasting only a few minutes. The side effect were relatively mild and a CT scan (detailed X-ray analysis) of the sinuses revealed that as far as could be ascertained the tumour had completely responded to the radiotherapy. All seemed well for about 18 months when a recurrence of

the original symptoms suggested that the tumour had returned. This was confirmed by subsequent X-ray examinations and a biopsy of the suspected area.

The dilemma now facing David is a fairly classic one in head and neck malignancy. Broadly speaking, there are two alternatives. By declining further treatment, he could accept the inevitable outcome of death. Survival would be for a year or at the most. The plan would be to continue to 'live in the fast lane' until the return of uncontrolled symptoms made this impossible. Alternatively, he could undergo major surgery. If the tumour were successfully excised it is possible that the patient may experience a normal or near normal life expectancy of good quality for another forty years. It is a risk analysis problem.

When I first met David I tried to think what would I do in this situation and asked my colleagues and friends the same question. Nobody could give me an answer and yet David had to make up his mind quite quickly over a period of about four or five weeks. It became clear as we sat and talked about this together in the clinic that any kind of immediate decision was impossible. Whilst I could carefully explain the treatment options using the consumer model, framework 2, but it quickly became clear that there was a difference between sitting and talking about it in a rather abstract way and living with this 'solution'. Deciding what to do in the clinic was a 'rational' decision but living and experiencing such a option might be very different. So he made a tentative decision to accept no further conventional treatment, to continue to 'live in the fast lane', and see what it *felt* like. We had together moved into a type 3 decision model, patient as researcher model, in which he would live life a little, live with this decision not to accept any further treatment and see if it was sustainable. We arranged to meet up together after two or three weeks to re-evaluate this option.

The interview I had with David occurred some time after the event and we were discussing what had been going on at the time when he was making these difficult decisions. I notice as I re-read these transcripts how directive I am in my questioning and for much of the time suggest what was happening and David acknowledges it.

Nevertheless, as a participant I 'felt' we were having a conversation where each of us was able to say what we really wanted to say-a sense of mutuality appeared to exist. I notice how difficult it is to prove this to others. At the end of the second section I notice that David chooses to offer an alternative explanation on what he might have done given the situation I was outlining. This and other occasions where he resists my interpretations suggest weak evidence that a degree of mutuality existed.

D: *I, I think I had almost made up my mind immediately I was, as I said earlier, not frightened of dying, I was a bit concerned about how painful it would be*

R: *Right.*

D: *Umm, very concerned for Linda and she, she, she is a very strong woman, she has been a marvelous support to me and she really has, she's liv' lived every day with it and she, she has been terrific. She's not cracked up at all.*

And later in the interview

R: *The other more complicated an issue that I have been experimenting with is the idea that you have, there's not only a lot of head knowledge about the treatment and your own life but you have a lot of what we call experiential knowledge.*

D: *Mmm.*

R: *I think you call that your inner voice.*

D: *Mmm.*

R: *And that, that we dialogue with one another*

D: *Mmm.*

R: *on the basis of head knowledge*

D: *Mmm.*

R: *but it is necessary for you consult your experiential knowledge*

D: *Mmm.*

R: *and listen to that*

D: *Mmm.*

R: *in order to make sense and to come to some kind of decision about what to do. It's no good being entirely rational about all this. That you had to, you had to experience, no, you have to kind of consult the experiential side of you to see if that, if it makes sense in terms of day to day living.*

D: *That's right.*

R: *I think the thing I really want ask you is, because I suddenly realised and I have asked you this question already and but I, will ask you again that when we had a discussion about what the right thing was to do, it seemed to me you did fairly quickly come to the conclusion that the most appropriate way forward was for you to, to carry on as it were without any surgical treatment, that it was one thing sitting in a clinic and deciding that that was the right thing to do*

D: *Mmm.*

R: *but it was necessary for you to go away and see what it felt like on a day to day basis with the knowledge that this thing still existed in your head*

D: *Mmm.*

R: *How would, how are you going to cope with it? How was your family going to cope?*

D: *That's right.*

R: *In other words you had to go away and <u>experience</u> this decision*

D: *That's right.*

R: *before <u>finally</u> deciding that it was the right thing to do. I don't want to put words into your mouth but I did sense that we talked and we quite quickly decided the right thing to do <u>but</u> there was still a lot of uncertainty in the air and then I saw you about 4 or 5 weeks later*

D: *Mmm.*

R: *and you came in, I remember thinking there's a strong feeling now that this is the right thing to do*

D: *That's right.*

R: *and that, that it had taken a few weeks of <u>living</u> with the decision before*

you, you felt certain you were right. Is that fair?

D: *Huhh. Ac', actually it was a fairly amusing time for me (laughter), I know that sounds ridiculous but it was. When we left here, Linda was in tears and she was very, very upset, she didn't know where she was going to go and I said come on, I'll buy you a drink and we went down to the pub, got, got her a stiff drink and I had one, came out and got in the car and she said you've not fastened your seat-belt up. I said well I don't do things like that anymore. She said what do you mean, you're breaking the Law. I said, well) there are no laws really, if I'm going to shuffle off in a year I'm now going to bloody well please myself for a year and we went home and we had the first of my 'Dave C's Dying Parties'. Rang round all the friends and said uhh (laughter), said that's it lads, if we're going to shuffle off you'd better all get round here and uhh literally within an hour of having left you, I'd got a house full of people and we had an enormous piss-up that went on 'til about 2 o'clock in the morning. Everybody had a fabulous time and uhh I think in a way that was my way of breaking everybody into the news and getting them laughing and looking at it in the right sort of context in a light sort of way rather than uhh being told in hushed tones that C's on his way out. And I think again (.) the circle of friends that I have helped me enormously because they didn't sort of walk round talking in hushed tones and they weren't you know sort of talking behind back hushed 'How is he today? and all the rest of it'. They*

R: *Mmm.*

D: *They were up front about it because I was up front about it, they sort of said well*

R: *Your openness made them open.*

D: *Yeah.*

R: *Yes.*

D: *What the bloody hell do you feel about this then Dave? How can you feel? I, I've talked about it a heck of a lot over the last year to all sorts of people because I find most people are very, very frightened by it and it, it, it*

helps people if you can talk to them and relate your experiences to them. Because I think in, yeah, in that sort of 4 or 5 weeks between saying no, no I'm not going to have the operation and seeing you again) umm

R: *You suddenly felt comfortable with the idea*

D: *Yeah.*

R: *and, in a, in a way that you hadn't. It struck me as, as it's all very well talking about these things*

D: *That's right*

R: *but then the moment you leave the room or you find yourself alone, you think, am I, am I doing the right thing?*

D: *That's right.*

R: *But that sense of uncertainty seemed to go.*

D: *Yes it did. I uhh, huhh, I talked it through with Linda obviously*

R: *Right*

D: *Uhh and it wasn't something that really she could make an input on. Decisions like that are very personal, you can only make them yourself. But I think she was not happy to see me go either route but uhh on a spiritual level, I think she was quite relieved for me not to have the operation because she having known me for all the years, she knows what that would have done to me mentally uhhh. And I think in fairness, she's got lots of faith in me, she's got none in spiritualism at all or that, or all that sort of thing but uhh, I've been a reasonably strong minded individual most of my life and*

R: *If you'd found though that we made a decision in the*

D: *Mmm*

R: *clinic or at least you'd made a decision to do nothing*

D: *Mmm*

R: *as the right thing and you'd gone home and you'd suddenly found that it was forever there, forever destroying your ability to enjoy yourself*

D: *Yeah.*

R: *and it was wrecking your family and that the idea of doing nothing was in living terms unacceptable, do you think you might have revisited the idea of*

surgery and said well OK go for it kind of thing.

D: *(Long intake of breath.) I think I would have, huhh, if it, I mean no', nobody likes pain. If it had become extremely painful*

R: *That would have been different, yes,*

D: *I think*

R: *moving the goal-posts.*

D: *Yeah, I , I , I don't know whether I would have reconsidered it or not. I'd like to think that I wouldn't because huhhh, in coming to the decision what I was actually saying is that I prefer life as I've always known it*

R: *Yes.*

D: *and I'm not prepared to carry on with uhh a much depreciated life form, not being able to communicate and all the rest of it so I think had, had I considered it through pain, I would have thought it was a fairly cowardly thing to do and had I, had I actually had that operation and woken up with the bits of tissue missing that they said would be missing, even if I had been slightly more comfortable, I think I would have been very disappointed in myself.*

R: *Mmm*

(Appendix 1, David)

When we had met again, four weeks later, he returned and almost before he started to speak I could see that things were different. Gone was any uncertainty he had about what to do. He felt completely happy with the choice he had made and any lingering doubts he might have had about entertaining the idea of major surgery was gone. Up to this point the process of shifting from type 2, consumer model, to type 3 patient researcher model was no different from many other similar clinical interactions. But the relationship I was having with David was different from other patients and I asked him if he would do something for me and he kindly agreed.

My increasing reflexive awareness had made me concerned that I might have been a party to creating a world where he appeared to be acting in complete freedom. Was I

operating using Lukes third dimensional power by creating a world for him of apparent freedom of choice and looking after his 'best interests' in this way? Were they in reality my 'best interests'? Torbert suggested action inquiry interested in transformation should "*actively seek(s), challenge and contradiction.*.....in every way possible-by taking on dilemmas of increasing complexity or social scope...or by discovering new ways of conducting inquiry that better show the consequences of his or her perspective and action....must be self mortifying. It would rather not influence than inappropriately influence."(Torbert 1991 p57) In this particular case it was important to me that this was at least tested in some way. So, I suggested to him that he obtain a second opinion and that we deliberately chose a department with a reputation for an aggressive attitude towards surgical treatments. He travelled to the Royal Marsden Hospital in London, saw a distinguished surgeon who fairly forcefully offered him treatment. I note that seeking a second opinion can still be construed as a third dimensional manoeuvre in that I was creating a more complex world of second opinion, in which he believed he was exercising judgement autonomously but was not. As it happens he did not change his decision and declined this offer of surgery. That is not the point I wish to highlight but instead I realised that for me things were now different. It is very unusual for a surgeon to ask a patient to seek a second opinion, so why had I done this?

Something had changed; I felt much more involved in a way that transcended the clinical problem. I was a researcher and participator in this enterprise and became aware of learning not just about medicine but about life in this situation. This dilemma, involving a man my own age, was forcing me to re-evaluate my own perspectives about death. I wanted to know as much as he did whether or not this was the right decision. I was also researching the nature of the relationship I was having with him as a doctor. I felt involved in an unusual way and our positions appeared to be equivalent in terms of power relations for at one moment David says;

"The prime responsibility for life, whether it be any facet of it, rests with the individual. I don't think you can go along and ask a doctor or surgeon to be responsible for your

health. You have to do it yourself. Whoever does go along to a doctor and says, 'Take me, do what you want', is making a big mistake."
(Appendix 1, David)

Paradoxically, such involvement is liberating in the sense that I feel I can return to practising at the level of 'technical rationalist'. I can once again say exactly what I think and feel about a clinical situation but both David and I accepted that I was not the only one with relevant and important information. My opinions become only one a perspective on a complex landscape and not a perspective that exercises dominance over all others. David appeared to exercise control over the situation and "join(ed) with the professional in making sense of the case and in doing so gain(ed) a sense of increased involvement and action." (Schon D. 1983. p302).

As one might expect this kind of interaction does not happen very often and I am still not sure that it really represents more than an exceptional extension of good feelings. However, I get the sense that even though this is not a common experience to feel like this, it is an ideal, a justified position, by which other clinical interactions are judged. So that, as I begin to get to know the patient and the problem in more detail, I begin to develop a sense that the clinical interaction is moving in this direction and use that as a weak judgement of progress.

Finally, this thesis itself might be evidence that a position of mutuality is possible in the clinical process. Virtually every thought has arisen in connection with the clinical consultation, or thinking or reading about the clinical consultation. As a consequence of this my whole understanding of what is meant by data, its relationship to theory, its relationship to values, its relationship to power has changed. I cannot claim to be a detached researcher of the clinical experience, free of bias and its effects, when the act of engaging with research results in such a shift of ontology. It suggests that my involvement with the clinical process is not only observing and researching, but participating as well.

Summary

I began this thesis by identifying the problem generated by apparently irreconcilable differences between quantitative and qualitative perspectives on the clinical landscape. My initial observations of hospital life suggested that adherence to a positivist epistemology to provide explanations was likely to be inadequate. In the methodology section I explored the theoretical foundations for different kinds of knowledge in five main paradigms and looked at different ways of generating data to enhance understandings. I conceived a three level conceptual model of working as a positivist, working as a constructivist and working as a researcher and linked these to the theoretical foundations developed in the methodology by suggesting that paradigm awareness was important. I have tried to show how this can work in the clinical situation to integrate quantitative and qualitative perspectives so that tailor making treatments becomes a credible possibility.

In the final section, Conclusions, I propose to evaluate what I have done (or not done) and how I see these findings in the wider perspective of my professional situation.

CONCLUSIONS

What did I set out to do?

At the beginning I asked myself why it was problematic to apply in clinical practice the medical findings I had been taught. Good quality clinical medical findings were obtained by studies that sought to exclude 'context', for context in this respect was to be regarded as bias. Difficulties arose when the moment came to restore such findings into context, because from time to time this context, this bias, would appear to exercise an important influence in determining what should be done. This could be seen in apparently 'simple' examples involving treatment decisions for tonsillitis to 'complex' problems in advanced head and neck cancer. To begin with, I appeared to have two alternatives. I could ignore the effect of context and follow current medical treatment guidelines outlined in books and articles or I could choose to ignore these guidelines and follow what 'seemed' to be the correct treatment, dictated principally by the context. My practice, until I began this thesis, had hovered between these two options; sometimes adopting the more conventional medical approach and ignore context and sometimes abandoning it in favour of issues raised by the context. I could detect no consistency, no pattern in determining which of these two broad approaches should be adopted.

What have I learnt from the exercise?

In the end my personal search did not result in a 'set of rules' that determined what should be done in every circumstance. Instead my hold was loosened on positivist medical knowledge as the only source of knowledge that deserved consideration by appreciating that positivist knowledge was dependant upon a methodology circumscribed by a particular set of assumptions. In developing as a qualitative researcher, I began to see the puzzle, not simply conceived in terms of problem in context, but reconfigured in terms of developing understandings of a host of non-clinical processes such as power, gender, group interaction. This meant recognition of different forms of data, particularly

a lighter touch on what constituted relevant 'knowledge', all of which illuminated the clinical landscape.

The thesis is essentially in two main sections and both these sections have been attempts at reframing the situation in a way that was non-positivist. The first part (the knowledge sections) attempted to broaden the definition of relevant data and the second part (methodology, clinical reflections and conclusion sections) attempted to develop a theory to generate better questions, better data and richer understandings. These understandings, developed in reframing the clinical situation, have been dependent upon different kinds of explanatory logics; comparative, developmental, descriptive and theorising explanations. (Mason 1996 p136)

Comparative explanations

In the early sections of the thesis, I suggested that the explanations of health and disease were not perhaps the 'science' that I believed them to be, but instead were merely perspectives fashioned by the science of the day. By tracing the history of tonsillectomy I suggested that justification for tonsillectomy was continually reformulated according to the scientific viewpoint of the day. This reformulation ensured its survival as a procedure in a way that made one at least ask the question; Are there other influences at play here that ensure the survival of tonsillectomy? I tentatively posed the question, could some of these influences be arising from a social process to fulfil a deep rooted need for magic, for risk, for sacrifice for whatever? In support of this, I showed how a similar operation, an adenoidectomy, and other surgical procedures, carried with them hallmarks of practice that suggested that they may not be so dissimilar from medical practice in other cultures that we regard as 'primitive'. I extended this approach to draw comparisons between an outpatient visit and a visit to a temple.

Developmental explanations

To arrive at a developmental explanation, I have tracked how and why I came to consider only positivist knowledge as worthwhile and worthy of attention. What were the educational processes that encouraged such a process? What role did the institutions have in achieving this? What might have been the purpose underlying such a transformation? The logic of explanation was centred on the educational process of rationalising knowledge that took place at school, medical school and hospital work but it also seemed to me that such developmental explanations linked in with the comparative explanations in a way that supports them. For example, the anatomy lessons that influenced my belief in what constituted relevant medical knowledge also prepared me as a modern day 'priest'.

Descriptive

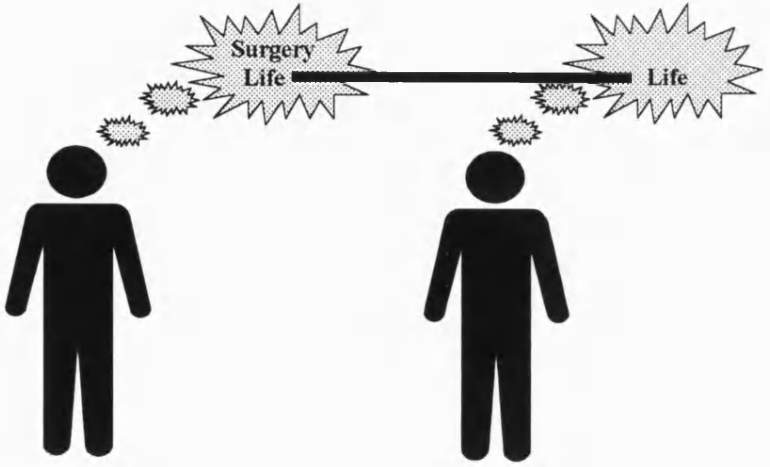
Mason advocates that all accounts are to some extent descriptive and "involve the construction of some kind of explanatory account of what is going on in a particular social location, or of the operation of a set of social processes." (Mason 1996 p136-138) The section Reflections on Clinical Practice offers explanations of the clinical scene in terms of 'groups', 'power' issues or the use of 'space', and I have come see these as key explanatory factors that underpin my understanding of what happens in the clinic and in hospital. The comparative, developmental and descriptive accounts cannot be regarded as robust explanation of social processes but I see them as constituting sufficient evidence from my perspective to disturb some firmly held assumptions. I have come to see comparative and developmental explanations as strategic frame experiments to assist in developing exploring social processes in the medical environment.

Theorising explanations

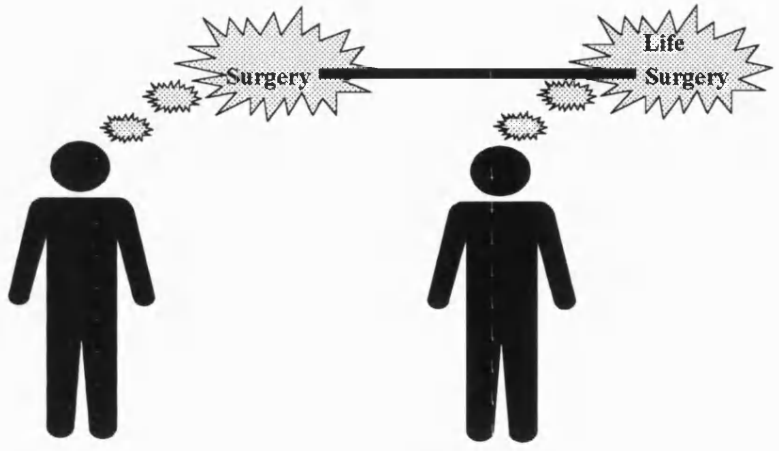
Finally, I relied upon theorising explanations for "any qualitative data analysis should have a wider relevance to some explanatory body of knowledge or social interpretation

and in this sense all explanations are theoretical explanations." (ibid). In this sense, a key part of my thesis rests upon a theoretical framework that suggests that positivist explanations do not have to necessarily compete with qualitative explanations as the only credible definition of truth. Instead the problem is seen as a paradigm puzzle in which it becomes necessary to *explore* which set of paradigmatic assumptions serve the situation. The limits that define the terrain of inquiry are illustrated by two clinical examples. In an emergency, when the patient is unconscious, a positivist approach to treatment would seem not only appropriate but obligatory. In the kind of situation faced by David, a constructivist approach that explored the importance of giving voice to data from other perspectives seemed to be more appropriate. In between these two strategies the shifting sands of what constitutes appropriate understandings and appropriate action invite me to explore each clinical encounter as a unique situation. In attempting to give theoretical shape to this spectrum of possibilities, I have produced a series of decision-making frameworks which are reproduced together in **Figure 8.** I have drawn attention to the way these four frameworks reflect the main paradigmatic positions of positivism, post positivism, critical theory and constructivism. I have also drawn attention to the connection between these frameworks and Torbert's leadership styles (Torbert 1991 p304). It follows that these four frameworks might depend upon a logic of explanation that is dependant upon theory but also illustrate the way that data, in the form of explanation here, may be theory dependant. Such a view suggests that limitations should be placed upon the importance of these frameworks. Of course there are many questions that remain unanswered, for example, how is the appropriateness of the framework determined and who decides this?

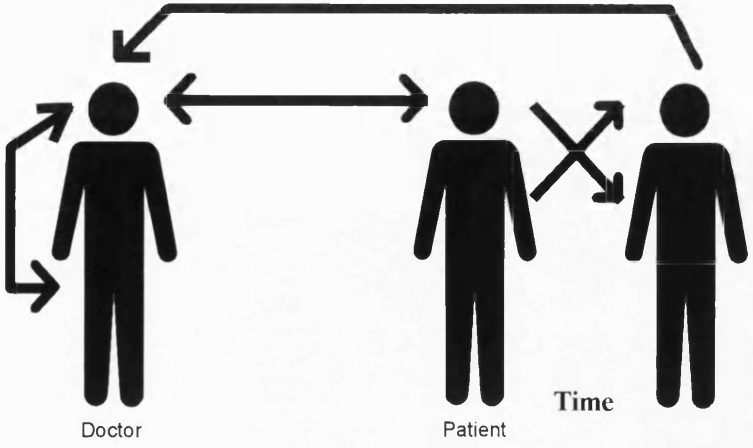
As I developed as a qualitative researcher, I came to understand that I was utilising a variety of explanatory logic, consequently many explanations, especially those dependant upon comparative and developmental logic, were in my opinion insufficiently explored and insufficiently shored up with data. When I re-read the thesis, I notice how I start to enter interesting areas, start to uncover explanations and then seem to stop. Furthermore such inference is not especially well connected with data and I may have produced an account that is not be sufficiently credible to others. Consequently, I ask myself as a



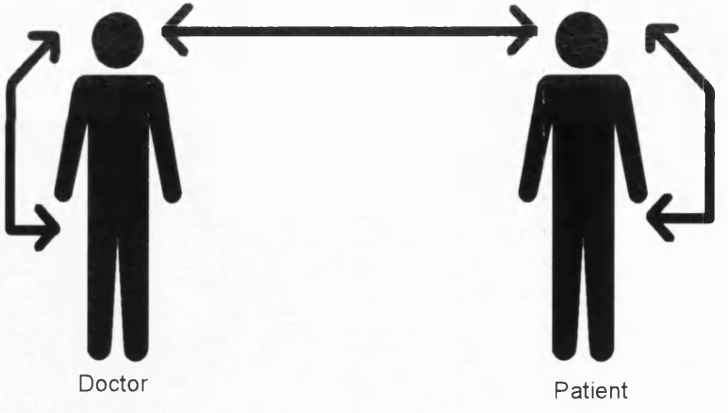
Type 1. The Observer/Healer



Type 2 . The Educator/Consumer



Type 3. The Patient as Researcher



Type 4. The Patient and the Doctor as Participators and Researchers

Figure 8

researcher, what could be the reasons for my insufficient and inadequate exploration of social phenomena?

Firstly, I now appreciate that I relied too heavily on the notion of privileged epistemological position. I tended to assume that, as a doctor, I was in a special position to observe, to notice, to comment about what was important and failed to substantiate this standpoint with data. In this respect my research process may have reflected my clinical process. Clinical consultations are short, dependant upon rapid and unsubstantiated inference, and in qualitative research terms lacking in time to develop substantial inquiry. I am suggesting my clinical behaviour (short consultations) is at odds with the research task (in-depth explorations). The second reason for this attitude may have been the data rich environment I was exploring. So many ideas and inferences were being generated by a qualitative approach that there was a tendency, hard to resist, to skip over them with insufficient critique. Thirdly, there is the argument already put forward that it may have been necessary to reduce criticality to shift paradigm. Finally, I spent much of my time trying, at a theoretical level, to integrate qualitative approaches and quantitative approaches without abandoning a medical science that I saw, on a day to day basis, as very effective. This puzzle may have distracted me from an in-depth exploration at a qualitative level because it implied the need, as I initially saw it, to abandon the benefits of a positivist approach.

What was the role of data in this construction?

The main body of the thesis is claiming a multi-paradigmatic perspective that includes critical theory and constructivist and in this respect the principal source of data were my own interpretations. This makes sense at one level because what was needed was a *personal* paradigm shift from positivism, but the self referencing nature of reflective practice may easily lack convincing transparency to others. Nevertheless, I began to recognise, as I shifted towards constructivism, the need to relate inference more closely with data, not only to produce a more credible account, but also to lay open the process of

explanation to permit more effective critique. Although there were attempts to do this, I acknowledge in retrospect that it was not done well.

Has my data constituted evidence in a literal/ circumstantial sense or does my data represent evidence of something else in an interpretive sense? In the early part of the thesis most of my data is interpretive and suggests a widening awareness of social processes in the clinical environment. An example of this is to be found in my suggestion that the social process of surgery may be evidence of some underlying process e.g.magic or sacrifice. Later on, my understanding of group dynamics, of power relations between patients and doctors and other issues are at least partly supported by evidence from the inquiry group and interviews. Nevertheless, I recognise as a qualitative researcher, that the extent to which my interpretation is disconnected from data needs constant attention.

When did the construction and development of theory take place?

Did the theory come first? No, for when theory comes first this involves stating clear hypotheses at the beginning so that "the analytical task is to develop and match up data against these clear hypotheses." (Mason 1996 p 141-143) I didn't do this because I wanted to reach beyond my knowing practice. Using theory that I understood to do this might have been constraining rather than liberating. Also it may not always be possible to solve certain puzzles using frameworks in which the puzzle is set. I set the puzzle as one of positivism in context (essentially a positivist approach in itself) but reconfigured it to one of understandings in terms of non-clinical processes (essentially a constructivist approach). Some loss of criticality may have been a pre-requisite to resetting the problem in this way in order to make progress.

Did theory come last? In some respects yes and in some respects no. Such an approach involves scrutinising data to develop "explanations to make them fit." In one aspect theory did come last. It was during the resubmission that I fully appreciated, with sufficient clarity, the three layered conceptual model I have outlined in this thesis. On the other hand the research was constructed in such a way that the theory was implicitly built

into the research from the beginning. I was working as a clinician within an espoused positivist or post positivist environment (the clinic) and working as a researcher within an espoused constructivist environment (the postgraduate research group at the University of Bath). This dialectic suggests that theory, data generation and data analysis developed simultaneously. Such an approach needed to devise a method of moving back and forth between data analysis, processes of explanation and theory construction. This was inherent in the separate groups of clinic (data and interpretation), Hospital Inquiry (data and interpretation) and Postgraduate research group and supervision (theory generation).

Was the data illustrative or constitutive of my explanation?

I used data from the clinic, the hospital inquiry group and from three interviews to support my explanations. From my perspective as a reflective practitioner, the most important data was that obtained on a day to day basis in the clinic. I notice how hard it is to demonstrate that such data, usually but not always interpretive, is authentically illustrative of any explanation I offer. This is especially difficult given the time constraints of the clinic, which limit the opportunity for inquiry in the moment. In the end, much of the data I present from the clinic and the hospital inquiry group was data that generated some *change* in practice or challenged some change in practice. Since most clinical interactions do not result in a change of practice, the data was not representative of what took place most of the time in the clinic. Since the *purpose* of this thesis is to present a credible account as a qualitative researcher, I felt the need to give more emphasis to data that supports the practitioner/ research role (how I inquire as a reflective practitioner/ researcher). Although good research and good practice are not mutually exclusive, I notice that the demands of good practice are not necessarily the demands of good research.

I used the data in interviews in a number of ways. Initially the purpose of the interviews was to illustrate with data certain explanations that I believed were present in the clinic i.e. how patient thought about issues in ways that led to the development of the decision making frameworks. A good example of this, I would propose, is the use of the term 'gut

feeling' that all three interviewees highlighted as important in making decisions. The interviews, separated by an interval of nearly four years, show a progression from a semi-structured format to a more open texture. In the interview with David, there are sections of the interview where I ask him to authenticate my interpretation and models of decision making. The interview with Valerie is much less directive, so that issues arose much more spontaneously, for example the phenomenon of power and space in organisations. The later interview suggest that I was beginning to be more confidant in handling interpretation lightly rather than seek confirmation of interpretation through interview.

An interesting question to ask as a qualitative researcher is whether the explanation could have been developed without the use of data? In certain respects it had to. The first part of the thesis, concerned with the reappraisal of knowledge was developed by searching for explanation without 'data' in the credible qualitative sense. This was achieved by multiple conjecture whilst holding onto theory (positivism) more lightly as other theories were evaluated. I cannot think of another way that I could have achieved this and I am still left wondering what precisely were the conditions necessary for this to have happened.

How reliable is my report?

Reliability is judged on the basis of consistency and judging reliability depends upon the paradigmatic perspective of the researcher. To the positivist this report is unredeemingly unreliable. Nothing in the report constitutes 'evidence'. A constructivist might see that report supports the notion that the hegemony of medical truth should be challenged, recognises the connection between power and knowledge, and makes the argument for non-biomedical data to be included in the overall explanation. However, all these positions are embedded within constructivist ontology anyway and do not necessarily support my claim of a widened ontology.

As a qualitative researcher, I notice that the multi-paradigmatic perspective has set me a difficult task. In order to be more reliable there is an argument that I should have stuck

carefully to a recognised methodology that was reliable so my findings can be clearly demonstrated to reside within a certain paradigmatic perspective. This approach, I believe, might have constrained my awareness of ontological position developed, I sense, by switching back and forth from positivism to constructivism, from the clinic to the research group. So I ask, by producing a report that scored highly on the reliability criteria, would such a report have been valid. Would it have led to a multi paradigmatic perspective that permits me today to accept positivism and constructivism? Probably not but I do not know for certain.

I cannot finish this section without asking the question, what is missing in terms of reliability? When I read this now I am struck by the attempt to portray my position of espoused mutuality with the patient. Where is the irritation I feel sometimes as I sit in the clinic, where are the lapses of unilateral power as I pull the shutters down on mutuality with the patient and impose treatment? Where is the sense of exhaustion in trying to maintain a reflexive approach in the face of a busy clinic and irritated reception and nursing staff? These are areas of exploration that I notice I have been hesitant to develop and which I would now see as raising concerns about reliability. Any further development of this thesis would, and should, explore such important issues because such feelings an attitudes are constitutive of my clinical encounter.

Can I demonstrate that my analysis is valid?

Assessing validity means asking the question; Did I measure or explain what I claimed to be measuring or explaining? In tackling this issue it is necessary to consider the validity of each of the component processes that make up the research; validity of methodology, validity of interview(s), validity of data, validity of interpretations, explanations and conclusions.

Methodological validity suggests a logic of method well matched to the social phenomenon requiring explanation? Assessing this suggests a standpoint outside the position as researcher and outside the social phenomenon under investigation. Such a

superior standpoint might exist but I cannot claim this understanding. Instead, I look for coherence between the two processes. It seems to me that the clinical task as reflective practitioner means exploring understandings on a variety of perspectives on a situation; the perspective of the patient, the perspective of the doctor, the perspective of others such as nurses, relatives, parents etc on the disease. In addition it means illuminating all the non-clinical processes that determine how these perspectives interact with one another. The research task represents an attempt to place these perspectives in paradigmatic context by understanding the assumptions that circumscribe each of these viewpoints and looks to integrate them together. I would therefore offer the argument that a multi-theory research approach (an awareness of paradigm) was coherent with a research task that required a multi-theory practice.

How authentic or accurate were the interviews of what I wanted to show? I believe that the interviews were representative of what I wanted to show in a number of senses but fell short of genuine validity in others. I would hope that they demonstrated evidence that I was

- taking seriously data generated from paradigms other than positivist in the biomedical explanation; for example all three interviewees acknowledged the importance of taking time to make major decisions and relying on the qualitative process of 'gut feel' or 'intuition'.
- an awareness of power issues; these are implicit within the structure of the interviews (David's interview was fairly structured, Patrick less so and Valerie's virtually unstructured) as well as within the text.
- an awareness of assumption by raising the level of inquiry with questions like "do you agree that", "what is your reaction to my assertion that" and occasions when mutuality was at least approached when David and I touched on the subject of how patients and doctors can obtain personal and meaningful insights through illness.

In contrast, I do not believe they produced reliable evidence of other social processes that I touched upon e.g. the place of risk, the place of surgery as transition processes from

youth to adolescence, from fertile adulthood to infertile adulthood, from life to death or of the place of magic or sacrifice in a way that is perceived as valid.

Data in the form of interpretations, suggested explanations and conclusions were obtained from four situations; clinics, interviews with patients, hospital inquiry group and the postgraduate research group. Which set of data do I perceive as more valid? The data that might be perceived as the most transparently valid was the interview data because the transcriptions enable others to audit the connection between what was said and interpretations and explanations that arose from this. This was useful but in one respect I regard the interviews as illustrative of and supportive of interpretation that took place much of the time in the clinic. I would argue that the reflective practitioner interpretations made in the clinic, adjusting and testing practice, was of central importance but demonstrating this is not easy. In retrospect greater attention should have been paid to this process. How could this have been done? I would now consider making video recordings of my clinics and those of others. These could be shown to an inquiry group comprising the patients concerned, medical staff (nurses, doctors) and not just the postgraduate group in order to develop understandings. In doing this again I see the need to pay greater attention to the inquiry process of the group as it sought to make inference from data.

I have been impressed by the importance of interviewing patients who I had looked after as a means of exploring what has happened. Nevertheless, the weakness, as I now see it, of relying solely upon this method lies in the fact that for much of the time we are working at a level of espoused theory. Without data of what happened at the time (e.g. a recording of the consultations) and the perspective of others, it is much more difficult to explore theory in use. This is particularly relevant to consider because I have used two techniques of interpretive validity that have been criticised in qualitative research. Firstly, a claim that I have a special standpoint that grants me epistemological privilege because I am a doctor. I failed to be clear about distinguishing between claiming a special standpoint as a doctor (which I believe is justified) and claiming that my interpretations grant me epistemological privilege (which I see as unjustified). Secondly, claiming my

respondents have special epistemological privilege, This problem is not adequately addressed by checking interpretation with patients, so called respondent validation, because such a position means introducing other complexities; for example how free were the individuals to speak? A counter argument rests on two points. Firstly, they were the only other people present, which limits the opportunity for triangulation unless video analysis is sought. Secondly, when your life is threatened, it may be a unique case and such individuals may be able to claim epistemological privilege.

Have I fulfilled my responsibility to produce good quality research?

I have come to realise that I chose a very difficult area of research and I have struggled to produce good quality research in a way that is transparent. The reason lies in the nature of such an account. Its basis is a personal account that justifies a transformation in what I perceive as relevant epistemology and useful methodologies to create a new personal ontology. This transformation has not been easy and may be a reflection of my lack of willingness as a researcher to let go of cherished ideas but it may also be a reflection of the pervasive nature of the positivist viewpoint.

What kind of generalisations can I make?

Generalisations have been classified into two types; empirical generalisations and theoretical generalisations. (Mason 1996 p 152) Empirical generalisations are dependant upon validity of sampling, so perhaps it is sampling strategy that largely determines generalisability. Since the sampling strategy was sometimes illustrative, sometimes typical or sometimes indicative of a change in practice approach, it is unlikely that others would consider this work robust in this respect. In terms of theoretical generalisation, I feel on stronger ground. I have used a three level research concept of positivist, constructivist and researcher that may deserve wider attention. The emphasis in the thesis on theory also reflects the considerable difficulty I have experienced in developing a credible theoretical position that allowed me to pay attention to qualitative data whilst continuing to honour the importance of positivist medical approaches.

In considering generalisability, I am obliged to consider for a moment the medical research environment in which this study was undertaken. How well does this study match up at a theoretical level with the approach that might be adopted by others in medical research? How well does it match up to other qualitative research approaches in the medical literature? There are three points to consider here. Firstly, how circumscribed do I propose to make this search; how wide is my field? Is it fair to simply look at qualitative research undertaken by other ear, nose and throat surgeons in the United Kingdom? Alternatively, should I extend the search further and review all qualitative research undertaken by any healthcare worker, psychologists, public health researchers or social scientist? Secondly, since the field of qualitative research is moving rapidly, do I consider the theoretical approach adopted by mainstream qualitative medical research in 1998 or the position in 1991, when I embarked upon the study? Thirdly, do I examine research output between these years? I propose to look at all three positions in the following manner. Firstly, to look at current research methodologies in primary care from a methodology textbook published in 1997. Secondly to examine the qualitative research from the last eight years that has found its way into mainstream reference sources. Thirdly, to examine qualitative research from the Cochrane collaboration, which is a world wide research database of systematic reviews, reviews of effectiveness, controlled trials register and methodology databases, and an organisation that claims a position of research quality.

What is the present position in terms of methodology in primary care? In answering this I have consulted a contemporary textbook on research methods in primary care. (Carter & Thomas 1997). The spectrum of methodologies considered suitable include

- *observation,*
- *interviews* (unstructured, semi-structured and focused),
- *ethnography*

- *pathography*. (Parthography is "more or less the use of detailed description of diseases in individual cases to enhance an overall understanding of people and their diseases." (Bradley 1997)

Bradley advocates that many of the skills needed to become a good ethnographer are already possessed by those in general practice and justifies this by arguing that general practitioners are familiar with;

- taking case histories as a main investigative tool;
- taking social and personal histories,
- allowing patients to express the meaning of events
- seeing patients in their cultural context
- already belonging to the community under study
- open minded (few pre-conceived) notions
- open to the unexpected.

(ibid)

He sees these skills as components of good ethnographic research. He suggests that with some adaptation "mainly as regards the extent to which the respondent is helped and encouraged to respond to the interviewer in a way that ignores his or her status as a doctor", (ibid) these skills can be reconfigured as an ethnographic research methodology. The constructivist might argue that this is an unjustifiable simplification for it is not possible to 'ignore' the status of a doctor in any situation, be it research or otherwise. Bradley's approach suggests adherence to some features of the dominant biomedical paradigm, which Gordon identified by seven basic premises.

- Scientific rationality
- Emphasis on individual autonomy, rather than on family or community
- The body as a biochemical nachine
- Mind/ body dualism
- Diseases as entities

- Emphasis on the 'visual'
- Reductionism and the seeking of universals

(Gordon 1988)

At heart, Bradley's approach suggests continued separation of researcher from researched, by looking to exclude the bias generated by the 'status of the doctor'. If separation of researcher and researched is the ontological perspective (essentially post positivist), what social phenomena does he consider are the objects of research? Bradley argued that qualitative methods are thought to be good for

- study of explanatory models
- comparing different perspectives of different groups (e.g. doctors and patients)
- identifying social networks
- study of medical pluralism
- study of deviance
- understanding behaviour of social groups.

(ibid)

If research into these components of social phenomena form the basis of qualitative medical research, what sort of output has been generated in surgery in recent years by such an approach? On a Medline search just over 116,000 research articles on surgery had appeared over the last five years, of these 434 claimed a qualitative component to the research project. The basic methodology employed by the vast majority of these studies turn out to be structured or semi-structured interviews to develop explanation.

A significant proportion have employed closed question interviews over the phone to ascertain satisfaction following treatment. These ranged from satisfaction after breast implants (Coleman-EA, Coon-SK, et al. 1995) to satisfaction with pain relief following surgery. (Kleinbeck-SV & Hoffart-N 1994)The use of semi-structured interviews was also widespread. These were also used to establish patient preferences for treatments (Bretones-Alcaraz-JJ, del-Pino-y-Pino-MD, et al. 1997; Stern-EB, Ytterberg-SR, et al.

1997; Bjerre-BD, Johansen-C, et al. 1995; Francke-AL & Theeuwen-I 1994) or the organisational quality of the service (Burkey-Y, Black-M, et al. 1997; Evans-D & Farquhar-C 1996; McComas-J, Kosseim-M, et al. 1995; Van-Damme-R, Drummond-N, et al. 1994; Mellor-J & Chambers-N 1995). A number of studies used semi-structured interviews to develop 'themes' that could become the focus for other research studies (Karlsen-B 1997; Jankowski-S, Videka-Sherman-L, et al. 1996; Kristensson-Hallstrom-I & Elander-G 1997; Carter-BJ 1997; Schaper-AM, Hellwig-MS, et al. 1996). Of more interest were a few studies used semi-structured interviews in an exploratory manner to investigate patients perceptions such as the role of 'faith', or 'turning moments for recovery' after major illness or surgery (Shih-FJ, Chu-SH, et al. 1997; Shih-FJ 1997; Camp-PE 1996). A relatively small proportion of studies departed from the semi-structured interview methodology and employed 'in depth' interviews with small numbers (n=3 to n=29) to generate 'themes' or 'content analysis' largely identified by the researchers themselves. These included attitudes of mothers towards pain in their children following surgery (Gedaly-Duff-V & Ziebarth-D 1994), breast reconstruction and expectations (Kasper-AS 1995) and the 'experience' of living with chronic liver disease (Wainwright-SP 1997). One study examine non clinical influences affecting treatment decisions in dentists (Kay-EJ & Blinkhorn-AS 1996), and another explored coping strategies of work pressure versus family life pressures in general practitioners (Rout-U 1996). One interesting study sought to explore the significance of 'subjective' symptoms, without any physical signs, of women who as a consequence went on to have a hysterectomy (Marchant-Haycox-S & Salmon-P 1997). Open ended interview methodologies were much less common and were described in a variety of ways; open ended, extensive or structured open ended. These generally concentrated on satisfaction with treatment or services (Miyata-R 1985; Rossen-BE & McKeever-PD 199) and one explored cross cultural attitudes towards pain (Kodiath-MF & Kodiath-A 1995). I found two studies that had utilised focus groups. These groups were used to generate 'concepts and themes' that were then incorporated into action. One charted the start of a self help group (Cury-SE, Ferraz-MB, et al. 1995) and the other a pilot study to developing semi-structured interview methods for a main study (unspecified) (Flanagan-PJ, McGrath-MM, et al. 1995).

The only example that appeared of a more co-operative inquiry methodology that appeared in the Medline search was a study to examine factors that led to an empathetic approach in physician consultations (Suchman-AL et al 1997). Twenty one physicians recorded on video a single consultation. Transcripts were made of these and both the transcript and video shown to all twenty one doctors. A group discussion led to a consensus of agreed themes at the end of which an empirically derived model of empathetic communication was developed.

The final method I proposed to consider the current position of qualitative medical research was a review of methodologies in qualitative research found in the Cochrane database of controlled trials. The title 'Database of Controlled Trials' suggests a positivist paradigmatic position but the organisation has an espoused purpose in developing high quality qualitative research in the medical field. In this database (Cochrane 1998) qualitative research that overlapped certain areas I have attempted to cover in this thesis was found. These include;

- patient/ physician communication (n=21) Review (Stewart 1995)
- how data presentation can determine choice (n=5) (Mazur 1997; Llewellyn 1995; Mazur 1994; Mazur 1993; O Connor 1989)
- patient's perspective in disease (n=4) (Pearlman 1997; Rodriguez 1996; Simpson 1995)
- care giving and researching (n=1) (Cattorini 1993)
- power and empowerment in the clinical setting (n=2) (Kubsch 1997; Davidson 1997)
- relationships with other healthcare professional. (n=>100) Review (Zwarenstein 1997)

The methodologies employed in these articles and reviews were;

- *observation* with 'category analysis'. Such categorisation enabled statistical analysis to be undertaken.

- *questionnaires,* largely structured
- *focus groups,*
- *intervention effects*

This last methodology, intervention effects, involved a baseline assessment followed by randomisation (with controls) and post intervention assessment. For example, in the review on patient/ physician communication eleven of the twenty one studies utilised this approach to assess the effect of a variety of approaches on communication. Interventions included seminars, training sessions and information packages. This approach, with a study design that is positivist in conception, was felt by the author to be more valuable than studies using a methodology based on observation alone.

From this brief review, it would seem that most qualitative research in mainstream medicine in the last few years appears to be positioned fairly firmly in the post positivist paradigm. Institutions such as the Cochrane Collaboration, an influential agency that defines quality in medical research, places significant emphasis on the importance of the defining control groups, the procedures of randomisation, statistical handling of data, replicability and the generalisability of results even in qualitative research. Such a methodological approach contrasts with the approach adopted in this thesis.

How have others responded to my research and explanations?

On the few occasions I have chosen to explore some of these ideas with my colleagues, it has produced varied results. In a study day for trainee general practitioners I was asked to discuss a number of apparently simple clinical scenarios. With the approval of the course supervisors, I chose to highlight some of the problems generated by such clinical situations by drawing attention to models of power. For example, one situation was to discuss what should be done when a patient "demands antibiotics for sinusitis." The usual approach would be to discuss the evidence in the literature for and against such treatment but instead I expanded the interpretation of the situation to ask questions about power issues. The feedback given by the trainees to this approach was mixed. Whilst three

quarters felt there was a place to discuss such issues, a quarter felt it was inappropriate and that literature evidence alone should form the basis for treatment. One talked of "too much philosophy and too little medicine" but there were others who said that it was about time such issues were raised as believed they formed an important part of medical practice. Overall, this response was disappointing because I had perceived such a group as open to a discussion of non-clinical issues-still making assumptions! In the course for trainee surgeons at Oxford, I have started to suggest the importance of non clinical processes like 'power' in decision making and the response is generally less favourable. Barely half consider an understanding of power as important in the clinical encounter. Recently, I was asked to spend a session on the subject of tonsillectomy with some senior surgical trainees. Instead of the usual approach based on recent literature reports, of which there are plenty, I chose to view tonsillectomy in a historical and cultural context. I used the operation of tonsillectomy as an example to show how theory reconfigured itself in the face of disconfirming data to maintain the concept of tonsillectomy. We then explored power issues surrounding listing for tonsillectomy in adults and children and linked this with power issues surrounding medical knowledge and medical organisations in general. To my great surprise, the feedback was remarkably positive. I wondered whether it was because all of the trainees were involved in seeing patients with tonsillitis, usually perceived as a straightforward problem but in reality not, that such an approach had touched a nerve. However, by the time I had read the feedback, they had all gone home and it was too late to ask them further questions. In that moment I appreciated that all the old problems encountered in this research were still there; assumption on my part about what I was expecting from them, and short experiences that limit the opportunity for inquiry.

What I have learnt from undertaking this thesis is the argument that it may be necessary for good practice to hold onto paradigmatic positions more lightly. Consistent with this position is the view that any interpretation within this thesis must be regarded as a standpoint that ought to be challenged, so I welcome dissent. After all, as Foucault maintained, resistance to knowledge generates further understandings. I have also learnt to really appreciate the unique situation of each clinical encounter, a pre-requisite, it

seems to me, of good practice, and the essentially illusory nature of understanding the medical scene.

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I would like to start with my family. I do not want to acknowledge my family's help in preparing this work out of a sense of duty, but do so out of a sense of thanks and love. I have a busy job, which makes great demands on family time, and I was undertaking research that I didn't need to do. It was, if you like, an indulgence. And yet, they were always very supportive and for this I am genuinely appreciative. Julia read sections of my thesis, and her perspective as a lawyer, MBA graduate, and my partner, gave me much to think about that was invaluable and impossible to obtain from anyone else. My children Rachael and Laurie were amused to see that I have quoted experiences with them in the thesis. Watching them grow and seeing how they learn, gave me a unique opportunity to look at my own attitudes to learning, which made me appreciate how much of what we believe are 'truths' are simply learned perspectives. I occasionally tried on ideas with them and they gave me feedback with the honesty that only your children can give you. I forgive the groans that occasionally arose when I went off to the word processor instead of playing football or tennis. I hope they forgive me.

Peter Reason and Judi Marshall have taught me to take intellectual risks. I have never met two academics prepared to so often entertain the extraordinary in the interests of discovery. It takes courage to take a position, which can be ridiculed, and I saw them frequently do this in my defence and that of other students. Their special qualities came out when we met up after I had been asked to resubmit. It was a difficult time for me and perhaps for them but their optimism that the process could be interesting, coupled with their belief that I had something interesting to say, will always be with me. I am very grateful to them.

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APPENDIX 1

DAVID

Richard: David thanks very much for coming. I um, cough, umm I am actually not quite sure how to go,

David: All right.

R: but I, I would just like to kind of recap your history and that means we first met a year ago

D: That's right

R: and that was 18 months I think after you'd first had your tumour

D: That's right

R: your tumour in your sinuses

D: Diagnosed Valentine's day 1991.

R: That's right. You'd had radiotherapy, you had initially done very well and then when we met a year ago we discovered there was a recurrence.

D: That's right.

R: And we were faced with a dilemma, at least you were,

D: Mmm

R: about what to

D: Mmm

R: in terms of further surgery

D: That's right

R: and radiotherapy was on the cards.

D: Yep.

R: Or the other was to try chemotherapy but I think Hugh ruled that out.

D: Yep.

R: The final alternative was to umm decide that umm that you would have no further treatment and that you would carry on with life and deal with the symptoms as and when they occurred.

D: That's right.

R: What I **(2)** what I am very interested to, to try and understand from is you is how, how you came to that decision.**(2)**

D: I think it's **(2)** it's not a decision that **(1)** actually comes out the moment that you're given the news and to understand a decision like the one I made, you have got to look back. Some of the things I am going to say to you are **(1)** so obvious it's just not true. Others might sound slightly bizarre actually but they, I'll, I'll tell you just the way it is.

R: That's, that's great thank you.

D: I think **(4)** in making any sort of decision, especially a momentous decision that might affect your life or your death, you draw on **(1)** all the years of experience that you've had in many, many fields and the decision that you make isn't based upon what you have been told, it's a lifetime's experience and I think **(2)** when I was about 7 years old, I was asked by a farmer to clear out a barn, he was a family friend and he was going to give me half a crown to clear everything out of his barn

R: Laughs

D: And at 7 I wondered up to, I'd shifted all sorts of stuff about and I wondered up to what looked to me like a little package on the floor and I picked it up and I walked with it and I walked for about 14 paces and then I went doing and stuck to the ground. I got hold of it and I tried to lift it and I pulled and tugged, couldn't budge it at all and it was a half hundredweight weight of one of the corn weighing machines and I thought how very odd. And as life has gone on, I, I had a, a landrover turn over on me and 6 men in Earls Court Arena and I picked the landrover up off these blokes and tossed it **(1)** adrenaline just fired up immediately. And when I was out in Singapore there was a religious sect out there and the blokes get knitting needles and stick them through one cheek and out through the other and they don't bleed and pull the knitting needles out and there's no scarring. And they hook meat hooks on the back and believe it or not drag great weights up the road and it doesn't tear the flesh and they don't scar. And **(1)** from being in my early twenties I thought well **(2)** this is very odd

(Coffee delivered)

D: I thought that's **(1)** that's very odd because there's obviously something more to these people than there is to us and I started to get interested in quite a few of the Eastern religions and read quite extensively on the Eastern religions and the power centres within the body uhhh and the fact that they believe in the power of the mind is probably the greatest power of all so I, I had already got a background of **(3)** I wouldn't really say wanting to believe in the power of the mind but I recognised it was there and I, I believe that obviously the mind controls the body, it's got to control the central nervous system, it's got to control the immune system and I have also got a great belief that uhh every disease that there is on earth, the answer can be found in the trees and in the ground so I **(3)** when I decided not to have surgery **(2)** there was that sort of knowledge permeating

around in my head. Also having served 10 years in the Marines, I've seen death in all sorts of guises many many times and it doesn't particularly frighten me umm I got to believe that I've got a responsibility to carry on for friends and family but for me individually, it's not a great problem I don't think.**(3)** I think the other thing that uhh horrified me about the sort of surgery that I was offered **(1)** and uhh

R: This was at the Marsden.

D: Yeah, yeah. **(2)** and the sort of state it would have left me in, I mean, to to have all the sort of tissue removed between the roof of your mouth and the base of the brain doesn't leave much of a bloke left,

R: No.

D: and I have always again believed that life is all about communication and and being able to look somebody in the eye and getting a feel for them and when you look at somebody

R: Mmm

D: they say that the eyes are the mirror of the soul and it's true you know . Life, life is made up of many many things but I believe that communication is one of the most important things and I certainly wouldn't want to give that up **(2)** so I, I, I was left actually having thought about it long and hard **(1)** umm **(1)** with the decision that perhaps my family didn't like very much at first, I'm sure they didn't, but uhh for me it was the only way out. I think other **(1)** things have come into play as far as I'm concerned as well. I believe that the prime responsibility for life, whether it be any facets of it, rest with the individual. I don't think you can go along and ask a doctor or a surgeon to be responsible and totally responsible for your health. I think you've got a great input into it yourself. I think that anybody who does go along to a doctor and says, well, "here I am, take me, do what you will, you can make me better and it's nothing to do with me" I think are making a big mistake actually. **(1)** Uhh **(4)** At the same time as I was being treated for cancer **(1)** I also had a friend in Exeter who was also treated for cancer and I think he actually, you know the uhh the short time when they gave overdoses of radiation

R: Yes.

D: I think he caught one of those, got cancer of the nasopharynx and uhh he died, died shortly after I had finished radiotherapy but uhh his wife asked me if I would go down and see a spiritualist faith healer in Wales ,(2) don't know about that.

D: I asked her initially if, if, if Trevor had seen him, this is the bloke that had the cancer of the nasopharynx and she said "oh yes he did" and said bloody good advert then, he's dead **(1)** and she said yeah, when he went down, he did say to Trevor immediately that there was nothing he could do for him **(1)** his allotted life span was up he was going to go out and help him to go out painlessly which all seems fairly bizarre at face value but apparently Trevor's mother went down there with glaucoma and came away cured and his daughter who's 21 went down there with a Bran's cyst in the jaw, I don't know what that is, but uhh apparently she was going to have to have it operated on and that cleared up so I thought in for a penny, in for a pound. So I went down to see this chap and uhh I, I had what he terms as 'healing' off him **(1)** and felt considerably better **(2)** umm. At that time

the **(2)** tumour hadn't manifested itself again, it was after radiotherapy but before **(1)** umm I got it in the neck and the **(1)** just in front of my ear there **(2)**. But I had got great problem with my left eye. The vision was down to **(1)** no more than 5% I reckon at that time. It was blood shot all the time and it was acutely painful, very, very dry, uhh, extremely light sensitive and after one visit to this bloke, it was all right again. Slightly blood shot but visions **(1)** I'd say 95% again and I thought, that's fairly odd, (*laughter,*)

R: Mmm

D: Very odd in fact. **(2)** From there, I took a lot of time off work, had 3 months work out actually and I started to read all the great Eastern religions again, brought books all over the place and I started to have a look at spiritualism. Umm and it was fascinatingly similar to a lot of the Eastern religions **(4)**. From the reading of the books, I eventually **(2)** put a little bit of credence in what was uhh being said and I tried to see this faith healer that I had initially seen down in Wales again, it's a long way, he's an exceptionally busy man, people come from all over the world to see him and uhh it was getting more and more difficult to see the bloke so eventually I went locally to the spiritualist church and umm they have been giving me healing down there on a **(2)** weekly basis for about **(1)** 10 weeks now **(1)** during which time I have improved enormously. You, you can probably see the lump in the side of my neck, I don't think that's huhh, since you last saw me I don't think you'd see a great difference in that.

R: I think there is virtually no difference since I last saw you.

D: There was an incredible difference, I had a heck of a lot of stress around uhh December. As you know I've gone bankrupt and one thing and another and I had to sell my house. My house was falling through and uhh **(1)** the whole thing was going array and it put me under <u>enormous</u> pressure. I got this terrible aching in my neck and this thing bloomed, it really did and it was only once all the aggravation had gone away, I could sort of put my mind on getting it all together again that it started to recede a bit but uh **(3)** that's basically it. If, if there's anything you would like to ask me I would be delighted to answer.

R: Very much so, thank you. Umm what it seems to me you are saying that umm whilst you you hear what is being said to you medically

D: Mmm

R: when we, when we discuss treatment etc

D: Mmm

R: that it is important for you to place that in the context of your own life and your own beliefs

D: That's right.

R: that you, you're not the kind of man I think I would expect to be told what to so. You, you take information and you decide how you are going to use it.

D: That's right.

R: I think that's **(2)**, I think that the way a lot of people feel but what suddenly, why I wondered about

D: Mmm

R: and I would very much like to ask you was, and, and I, I really only realised it when I was talking to you was that there is a world of a difference between sitting down and rationally working out in your head what is the right thing to do

D: Mmm

R: and I think, I got the impression quite quickly that you decided you weren't going to have any conventional surgical treatment,

D: That's right.

R: That the, that the notion of continuing as you were was acceptable to you but you weren't sure how you feel about that in everyday life, how you feel your family would cope

D: That's right.

R: and I, I got the sense that you needed to test it in day to day living for a few weeks to see what happened. Is that fair or not?

D: Huhhhhhh.

R: If for example,

D: I, I think I had almost made up my mind immediately I was, as I said earlier, not frightened of dying, I was a bit concerned about how painful it would be

R: Right.

D: Umm, **(2)** very concerned for Linda and she, she, she is a very strong woman, she has been a marvelous support to me and she really has, she's liv' lived every day with it and she, she has been terrific. She's not cracked up at all.

R: You're, you're one of the few couples I've come across where their relationship seemed to be enhanced by this sort of problem.

D: Mmm.

R: Most it manages to destroy.

D: Mmm.

R: Very impressive, please go on.

D: That uhh, I think that was one of my main concerns **(2)** that ooh crickey, balancing

the books and deciding. I suppose one of the other things that figured quite largely with me is that I've got a massive life insurance policy so even though I had gone bankrupt at the time, it, it, this didn't figure in the decision. It was a comfort to know that if I did die, Linda would be looked after and looked after very, very well. So there, there was that element of it and there was also the huhhh, I, I've seen a couple of horrendous deaths actually. I had a friend of mind, won't say, won't, won't give his name, who had a stroke at the age of 61 and he was married to a woman who was 20 years his junior **(1)** and from having this stroke the relationship, as you say, just went and she treating him in the most appalling way and it, it, it, the poor bloke

R: Mmm

D: he, he couldn't communicate properly, paralysed down one side and *("imitating groaning noises")* as he tried to talk and she used to talk for him all the time and uhh he's slobber down his shirt and she would go "Geoffrey for goodness sake look at the state of you". And this poor bloke got lower and lower and lower and eventually starved himself to death and wouldn't take a pill or anything, he just stopped eating and I looked at that and I thought, no that's not for me. That's existing on the worse possible terms that you, you could and I also watched my father in a teaching hospital in Sheffield, for a year he had every possible test that you could every devise I think uhh he finally went out with lymphoma **(1)** but again I looked at him and I thought that this is blood cruel that you've got this bloke, he, he uhh, he's like a trapped rat, he's been **(1)** having needles stuck in him and things up his bum and all sorts of things, the poor bloke was in great distress for a long, long time **(1)** and, I wouldn't want to go like that either.

R: Right, so that, that, for you that's a big issue, how **(1)** the, the, the process of succumbing would be.

D: Yes that's right.

R: Because umm, **(2)** I've said, I mean I, I kept asking myself time and time again, what would I do if, if faced with your dilemma because you were, we're the same age virtually

D: Mmm

R: and umm, and to cover that, that kind of hits you as a doctor, you, you, if you see somebody who is very much older
D: Yeah. *(laughter)*

R: and sort of say well that's, that's not my problem but I, but we were the same age and I keep asking myself, what would I do and I couldn't really **(1)** put myself in your position. I could kind of work out what I thought I could do and I asked lots of friends what, what they would do

D: Mmm

R: I asked without mentioning your name, I

D: Mmm

R: would describe the situation and how would you resolve it. **(3)** It struck me that,

umm that it wasn't something you could work out in your head

D: *(Long intake of breath.)*

R: but it, it seems to me talking to you that, quite a lot of, of it has been worked out in your head.

D: Huhh. I, I, I don't think it's so much worked out Richard. I think it's uh as I said before, it's a lifetimes experiences and you draw on them and umm, even though something hasn't affected you directly,

R: Mmm.

D: it's every day sort of what could happen to you and huhh

R: Right.

D: you pull them all together **(2)** and it helps you to formulate decision and I think **(1)** obviously a year on the decision I made was incredibly right.

R: Yeah

D: And I, huh had I not made that decision I would have been up to Royal Marsden and they, they would have had the knife in me and umm, I'd have been in a fairly poor state, in fact I'm quite sure that had I had that operation I would be dead now.

R: Right.

D: I'd have just given up. **(1)** Whereas I think uhh, I'm reasonably confident that I've got quite a reasonable life span in front of me now.

R: Mmm

D: *(Laughter.)*

R: Was, was there at moment at which you, by the way I would agree

D: *(Laughter.)*

R: very strongly, I am very struck by how well you are. Was there a moment at which you, you thought "yes, I know what to do".

D: *(Intake of breath).* **(2)** When making my decision?

R: Yes. It's the, it's the processes by which you got there that I, I am very curious to understand.

D: Huhhh, I, I, I think perhaps I don't understand some of it myself . I think there's, we've all got a bit of an inner voice, women call it female intuition, men scoff at it, huhh, but it's there and there was something within me that said "no that's not the route to go, you go.."

R: Did you, did you talk to that inner voice at all? Did you find yourself having a, a dialogue with it?

D: No.

R: You just listened to it.

D: I just listened.

R: And what do you see, what do you see, where do you see that inner voice coming from?

D: Well huhh, I, I meditate a lot now and I have done ever since I last saw you **(1)** and uhh, I'm getting, much, much more successful at meditation and **(2)** there is no doubt in my mind, if, if you go for spiritual healing, the healer will tell you that he draws on a power, nothing to do with him as an individual he can't do anything,

R: Yeah.

D: he's just a conduit, for **(1)** this power that comes off the ether as they describe it **(2)** and I've seen, one, two, three, four, five different healers now on various occasions, all from the same sort of areas. One was a crystal healer, uhh, I believe, that, that they do aroma healing and all sorts of rubbish but, I say rubbish, it's not rubbish, but they all say that the power comes from the same source and it's something that's tangible, you can actually feel it. Uhh. Have you ever watched anybody have healing or

R: I haven't no.

D: been involved? It, it's quite the incredible experience and uhh **(1)** one that I recommend *(laughter)* actually. But, you, you will get a healer and they will come and stand behind you and just put their hands on, on your shoulders for a couple of minutes and within second you can feel heat powering into your body now, i' i' i' it's not just body heat, you can actually feel the heat coming into your body and then they'll start, they'll hold their hands either side of your head about 6 or 7 inches away and they tell me that this is on the extremity of the aurora, the aura rather, and they, they follow it down your body and if you sit with your eyes closed, you can tell exactly where their hands are and just this, the heat that is generated by the hands,

R: Uh-huh.

D: is, **(1)** well it's beyond description really **(2)** and every, everyone that you see **(1)** you'd have an exactly similar process which says to me that there's, there's got to be something in it. It's uhhhm, it's evidential, it's there, you can, it's tangible, you, you, it's not a case of saying well it's a placebo effect and uhh **(1)** I just want it to happen, it, it does happen and I, I've talked to different people who have been waiting for healing and they all talk about the same experience and it, it's marvelous how many people you see that are cured of a wide range of illness and diseases so **(2).**

R: Your experience of all that, umm, much of that, although I suspect the stage was set for an interest in spiritualism

D: Without a doubt

R: Yep.

D: Without a doubt.

R: But a lot of that occurred after you'd decided

D: Yes

R: and were, it seemed to me, umm a development of what had gone on

D: Mmm

R: but umm **(1)** was, was something you did after you'd decided but, I, I just picked up an interest in what you said about your inner voice, which

D: Mmm

R: as you say, women have but men are inclined to dismiss

D: Yeah

R: that you listened to that.

D: I, I tried, I tried meditating. When you said the stage was said you were dead right I, I used to try meditating as long ago as when I was 23, 24

R: Right.

D: and I used to put half an hour a day aside and I wasn't very successful with it because I hadn't read anything on it, I really didn't know where to get any information on it so I just used to sit there and **(2)** right where are we now please.

R: Yes.

D: And uhh, it, it, it didn't take me very far but umm **(2)** yeah, I, I, huhhh, I think it's true to say that even when I first got the news I'd got cancer and I was having radiotherapy, umm I began to look inwardly a lot more than I had for many many years umm **(3).** And cert', certainly within business actually, I, now and again I used to listen to the inner voice, I didn't want to do something and say go on, no that's the right way and all

R: Right, I see. I', would you listen to the inner voice if it gave you umm advice that was irrational or contrary to what you might expect to do if you sat and tried to work it out?

D: If it was strong enough, yeah.

R: Yes. What would you do if there was a conflict? Which would you listen to?

D: Mmm, crickey that is difficult. I think I'd go for the inner voice.

R: Right.

D: I think I've huh gone off the gut for a great percentage of my life you know, you, you, you look at something and you think is it right, is it wrong, oh crickey, can't make a decision. The first thought is yes it was right, let's go for it. And it, it ,it ,it works the majority of the time I think.

R: Did you find that there is a difference between **(1)** what you think is the right thing to do and the inner voice? Do you sometimes wait until the two are in harmony and then go

D: *(Intake of breath.)*

R: do you find that they, they do match up with one another if you wait, or not?

D: I think I almost always convince myself. I find all the arguments that the inner voice'd use and present those and **(1)**

R: Right.

D: probably convince myself that it was right in the first place. *(Laughter.)*

R: *(Laughter).* Right. A, a thought occurred to me. When you first had the problem diagnosed and you were having radiotherapy.

D: Mmm

R: Did you start to think "what would I do?" if this problem comes back.

D: Mmm

R: So you, you were already starting to formulate in your own mind some kind of strategy

D: Yeah.

R: if there was a recurrence.

D: I didn't expect it to come back after I'd finished radiotherapy actually but during the course of the radiotherapy which I found very hard to cope with for the first few sessions

R: Mmm.

D: I certainly thought then, well you know, if this doesn't work **(1)** what's the road, how do we go forward, uhhh so I, I was already contemplating the fact that it may not work and I might have a fairly short spell to sort things out so yeah I had given it some thought.

R: But had you already, had you thought about the choices between further surgery and between deciding not to do anything or had

D: No not at that stage.

R: No.

D: I, I thought if I was, if I was going to shuffle off it would be the radiotherapy failing, I'd already been told that surgery was almost impossible and it

R: Right.

D: Uhh, and that if it failed it would be exponential growth and **(1).** I mean it, it was fairly well advanced actually when, when they started radiotherapy. It was through the side of my nose and into the uhh **(1)**

R: Eye.

D: into the eye and it's pretty painful.

R: Right.

D: so and uhh I think I knew what to expect with that.

R: What, how do you think you'd have coped if you'd met a surgeon who hadn't discussed with you the option of doing nothing? **(1)** Perhaps 'nothing' is the wrong word, of treating it conservatively or with alternative, none traditional **(1)** medical methods?

D: *(Intake of breath.)* Hooh crickey. That is a difficult one.

R: Could you have been sucked into the system do you think and , and not allowed your own choices or do you think you would have, you'd have, you'd have blocked that?

D: Yes I would, without a doubt. I think uhh **(2)** if, if, if you, you look at structured Western civilisation there are all sorts of organisations who would dearly love to run your life for your and *(Laughter)*

R: Right.

D: and try to on regular basis and, and I'm cognoscente of the fact that you, you could be aware of it all the time, uhh, so no I, I wouldn't be forced down any particular route I don't think.

R: Mmm. **(2)**. I'd very much welcome some feedback about the part I played. I mean

D: Mmm.

R: **(2)** umm **(1)** How did you view our relationship and the discussions we had? What was, what was the good thing, was was the bad thing, what, what, what

D: Well there, there, there was', there wasn't a bad side to it Richard, I was absolutely <u>delighted</u> that you were frank with me. Uhhh. I think you, you, you were very kind in the way that you put it. You, you didn't pull any punches but it wasn't brutal whereas the bloke at the, the Marsden Clinic, I mean that was a **(1)** disgusting carry on. Uhhh

R: Mmm

D: No, I, I, huhh, in all things I like honesty and in coming to see you, I asked you what the prognosis was and you told me. You told me probably the kindest possible way that you could without pulling any punches and I was very, very grateful for that. Umm. Had you not told me in that way and had I not found out for a fair length of time, I think I'd have been a bit annoyed actually.

R: Right.

D: Because at least it gives you a chance to well **(3)** I don't know, put, put yourself in order, start to fight it, start to make your decisions but in, in my view it was exactly the right way to treat it and the right thing to do.

R: Right. And I, I don't mind you, I really don't mind you being critical in any way because I'm interested to learn but would there be anything that you would have done differently or uhh is there anything that I failed to understand.

D: No. No, not at all. I think **(3)** there was just one, one, one element when I, I started to tell you about going down to see this bloke George in Wales

R: Yes, I know, I remember that.

D: "Don't Dave, don't tell me". *(Laughter.)*

R: Did I?

D: Yeah, yeah. *(Laughter).* And I thought well, come on Richard that's a bit closed minded. *(Laughter).*

R: Thank you. I think the trouble is, umm, I, I, I, I will try to be more open about these things. It's very difficult. What, what ends up umm is people start asking advise about whether or not they think

D: Yeah.

R: they should go but the trouble is, I have no experience at all.

D: No.

R: I don't, I don't know anything worthwhile about the set up

D: Mmm

R: and I **(1)** I am careful to only claim any kind of experience or knowledge or expertise in rather a narrow area but I am aware that there are, there's much more

D: Mmm.

R: to the whole business of disease, medicine and life with the narrow perspectives that,

the the Western tradition probably gives us

D: Mmm

R: but I have to be very careful about claiming to be an expert.

R: That's right. (*Laughter.*)

R: But, but, I, no I, I do sense that.

D: (*Laughter.)*

R: I remember thinking that I haven't handled that very well and that I, I certainly havn't been discouraging to you but I don't think I was being very outwardly encouraging and the other thing is also, I do see some people spend large amounts of money whizzing around trying to find treatments

D: Mmm

R: and, and again, one doesn't want to be part of umm that the practice that does that,

D: It's very hard. I mean, you, you, you have to depend upon your ability to cure people and if you weren't positive in that approach and you thought that you weren't going along the right route, you, obviously couldn't, couldn't function properly but uhh, **(2)** I, I'm not trying to sell spiritualism to you or spiritual healers but they certainly won't charge you.

R: Umm.

D: If you want to make a donation

R: You can.

D: a small donation, you can.

R: Right.

D: but they'll never ask for money. Umm. If you make a donation, they're they're normally quite emphatic that they will only take it if you can really afford it and by small, I'm talking about £10 for a healing session

R: Right.

D: which is not a lot when they have probably given over an hour, an hour and a half of their time to you.

R: Right.

D: Uhh, huhh. **(4)** It is a very holistic approach I think and again when you, when you go for spiritual healing, they will never say to you the medical profession is wrong, don't go there. They always say well what we are doing is ancillary so

R: Mmm

D: for goodness sake carry on seeing your doctor.

R: Mmm, that's the way I view it I have to say.

D: Yeah, which is fair enough.
R: Can I be very explicit in directly answering me about some ideas I've got about health and how to **(3)** and I'd be, I'd be very grateful if you think I've got it wrong.

D: Yep.

R: It seems to me that if we **(2)** take ourselves, that, that, we'll let that represent that as the doctor and that as the patient *(demonstrating with objects on the desk)*, that, **(2)** I know a lot about the disease and the surgery

D: Mmm.

R: and that it is a <u>much</u> more valid and easier process it seems to me to make a good decision on the part of the patient, to take the knowledge that I have about disease and enable the patient to transplant it into the context of their life

D: Yep.

R: than it is for me to take that, their lives and try to transplant it in the context of the disease,

D: Exactly.

R: so that I (.) regard myself as being an educator about disease and treatments and

D: Mmm.

R: and that it is (.) a skill in communicating this properly that it is up to you to place that in context and accept or reject as much as you want.

D: That's right.

R: That seems to me self evident although it's amazing how many doctors have trouble understanding this

D: *(Laughter.)*

R: The other more **(2)** complicated an issue that I have been experimenting with is the idea that you have, there's not only a lot of head knowledge about the treatment and your own life but you have a lot of what we call experiential knowledge.

D: Mmm.

R: I think you call that your inner voice.

D: Mmm.

R: And that, that we dialogue with one another

D: Mmm.

R: on the basis of head knowledge

D: Mmm.

R: but it is necessary for you consult your experiential knowledge

D: Mmm.

R: and listen to that

D: Mmm.

R: in order to make sense and to come to some kind of decision about what to do. It's no good being entirely rational about all this. That you had to, you had to experience, no, you have to kind of consult the experiential side of you to see if that, if it makes sense in terms of day to day living.

D: That's right.

R: I think the thing I really want ask you is, because I suddenly realised (.) and I have asked you this question already and but I, will ask you again that when we had a discussion about what the right thing was to do, it seemed to me you did fairly quickly come to the conclusion that the most appropriate way forward was for you to, to carry on as it were without any surgical treatment, that it was one thing sitting in a clinic and deciding that that was the right thing to do

D: Mmm.

R: but it was necessary for you to away and (.) see what it felt like on a day to day basis with the knowledge that this thing still existed in your head

D: Mmm.

R: How would, how are you going to cope with it? How was your family going to cope?

D: That's right.

R: In other words you had to go away and <u>experience</u> this decision

D: That's right.

R: before <u>finally</u> deciding that it was the right thing to do. I don't want to put words into your mouth but I did sense that we talked and we quite quickly decided the right thing to do <u>but</u> there was still a lot of uncertainty in the air and then I (.) saw you about 4 or 5 weeks later

D: Mmm.

R: and you came in, I remember thinking there's a strong feeling now that this is the right thing to do

D: That's right.

R: and that, that it had taken a few weeks of living with the decision before you, you felt certain you were right. Is that fair?

D: Huhh. Ac', actually it was a fairly amusing time for me *(laughter)*, I know that sounds ridiculous but it was. When we left here, Linda was in tears and she was very, very upset, she didn't know where she was going to go and I said come on, I'll buy you a drink and we went down to the pub, got, got her a stiff drink and I had one, came out and got in the car and she said you've not fastened your seat-belt up. I said well I don't do things like that anymore. She said what do you mean, you're breaking the Law. I said, well **(1)** there are no laws really, if I'm going to shuffle off in a year I'm now going to bloody well please myself for a year and we went home and we had the first of my 'Dave C's Dying Parties'. Rang round all the friends and said uhh *(laughter),* said that's it lads, if we're going to shuffle off you'd better all get round here and uhh literally within an hour of having left you, I'd got a house full of people and we had an enormous piss-up that went on 'til about 2 o'clock in the morning. Everybody had a fabulous time and uhh **(1)** I think in a way that was my way of breaking everybody into the news and getting them laughing and looking at it in the right sort of context in a light sort of way rather than uhh being told in hushed tones that C's on his way out. **(1)** And I think again (.) the circle of friends that I have helped me enormously because they didn't sort of walk round talking in hushed tones and they weren't you know sort of talking behind back hushed 'How is he today? and all the rest of it'. They

R: Mmm.

D: They were up front about it because I was up front about it, they sort of said well

R: Your openness made them open.

D: Yeah.

R: Yes.

D: What the bloody hell do you feel about this then Dave? How can you feel? I, I've talked about it a heck of a lot over the last year to all sorts of people because I find most people are very, very frightened by it and it, it, it helps people if you can talk to them and relate your experiences to them. Because I think in, yeah, in that sort of 4 or 5 weeks between saying no, no I'm not going to have the operation and seeing you again **(1)** umm

R: You suddenly felt comfortable with the idea

D: Yeah.

R: and, in a, in a way that you hadn't **(1).** It struck me as, as it's all very well talking

about these things

D: That's right

R: but then the moment you leave the room or you find yourself alone, you think, am I, am I doing the right thing?

D: That's right.

R: But that sense of uncertainty seemed to go.

D: Yes it did. I uhh, huhh, I talked it through with Linda obviously

R: Right

D: Uhh **(2)** and it wasn't something that really she could make an input on. Decisions like that are very personal, you can only make them yourself. But I think she was not happy to see me go either route but uhh **(4)** on a spiritual level, I think she was quite relieved for me not to have the operation because she having known me for all the years, she knows what that would have done to me mentally uhhh **(2)**. And I think in fairness, she's got lots of faith in me, she's got none in spiritualism at all or that, or all that sort of thing but uhh, I've been a reasonably strong minded individual most of my life and

R: If you'd found though that we made a decision in the

D: Mmm

R: clinic or at least you'd made a decision to do nothing

D: Mmm

R: as the right thing and you'd gone home and you'd suddenly found that **(1)** it was forever there, forever destroying your ability to enjoy yourself

D: Yeah.

R: and it was wrecking your family and that the idea of doing nothing was in living terms unacceptable, do you think you might have revisited the idea of surgery and said well OK go for it kind of thing.

D: *(Long intake of breath.)* I think I would have, huhh, if it, I mean no', nobody likes pain. If it had become extremely painful

R: That would have been different, yes,

D: I think

R: moving the goal-posts.

D: Yeah, I , I , I don't know whether I would have reconsidered it or not. I'd like to think that I wouldn't because huhhh, in coming to the decision what I was actually saying is

that I prefer life as I've always known it

R: Yes.

D: and I'm not prepared to carry on with uhh a much depreciated life form, not being able to communicate and all the rest of it so I think had, had I considered it through pain, I would have thought it was a fairly cowardly thing to do and had I, had I actually had that operation and woken up **(2)** with the bits of tissue missing that they said would be missing, even if I had been slightly more comfortable, I think I would have been very disappointed in myself.

R: Mmm.**(3)**

D: Not because I think it's bravado but we've all got to go out a some time and huh, not being able to live, I don't know, 6 months pain

R: Mmm

D: to cop out and have the operation and then live with perhaps, 10 years of uhh **(1)** a life that you're not really enjoying, wouldn't have been a fair trade I shouldn't think.

R: Do you feel there's anything you want to say?

D: **(4)** Mmm **(1).** Yeah, I wouldn't like to be your shoes *(Laughter)* because it was, it was very, very difficult. I know **(1)** you're dealing with all sorts of people from all sorts of (.) walks of life all sorts, all sorts of intellectual levels and whilst this might be all right for me, **(1)** there are an awful lot of people who come along and say 'Doctor, please doctor, you tell me what to do'. It must be very difficult when you have this sort of evidence to say well, mmm, that's all right for some and not for others but who are the some and who are the others?

R: I try very hard not to tell people what to do.

D: Mmm.

R: Because I think it's <u>so</u> difficult to know

D: What's right.

R: begin to understand the complexity of other peoples minds but I am very struck by the dignity of most people but you should also realise that I learned a lot from you. I have, I think, I mean, there are perhaps 4 or 5 people I can look back and think, gosh you profoundly influenced me and you are one of them and ummm each one of those removes to some extent the fear of death because at some point, I am going to have to confront these kind of issues

D: That's right.

R: Like you, the idea that you are immune from all of these problems is of course untrue. So it, if I see people like yourself handling it umm in an incredibly open way

D: Mmm.

R: it's umm, it's very, very kind of reassuring and it helps remove for me in particular, death etc and umm **(1)** people like you are very unusual and they provide great insights into what's happening and I am incredibly grateful to you. I, I've got at least as much, perhaps more out of talking to you than you have and that, that isn't, that's genuinely meant.

D: Good, I'm very pleased.

R: Thank you very much, it's very kind of you.

D: No problem at all. If I can be any, of any further assistance, then please give me a ring. I don't mind at all.

R: Thank you very much. Well, what, what might happen is when I look at this film or another doctor or maybe when my research group what this they'll think 'Richard, gosh uhh, he should have asked this, this is a fascinating question.

D: Mmm.

R: Umm and or you didn't pick up on something that David had said.

D: Mmm.

R: seemed to you important. If it is in order, if you didn't mind I might just drop you a line.

D: No problem.

R: That's very, very kind of you, thanks a lot.

APPENDIX 2

PATRICK

Patrick: Are we on now?

Richard: Yes. (3) Umm (3) I think, I think we umm (1) we ought to get on film a couple of things that we talked about beforehand

P: Yes.

R: about negotiating umm (1) this interview and how it was set up and umm one of the things that I (.) wanted to make clear was that umm the issues that we are going to discuss and we haven't fully negotiated what those are, were ones that we (.) we would be doing in a collaborative way and I'm not somebody researching a particular topic and you're the researched because I (.) umm I think you indicated that you were, were really interested in some of the things that we might have wanted to talk about. Is, is that

P: That, that's true yes.

R: OK. And uhh you are fully aware that this is umm part of my PHD.

P: Yes.

R: And that I have gone through some people who may, who are, who are possibly going to be involved in looking at it which includes my secretary who will be typing out the transcript and they'll uhh, they'll be my supervisors and my examiners.

P: Yes.

R: And, if I, if anybody else is going to look at it then that will be negotiated with you.

P: Fine, that's uhh understandable.

R: Thank you for accepting this and that at any time stop this and the camera and at any time you can tell me that, that what's just been said is uhhh doesn't go beyond us.

P: Right.

R: And that I'm going to provide you with a transcript of what's going on and the same applies

P: OK.

R: That's just to let you know that. I just wanted you to be sure about that. Umm (3) right well the, the agenda. (Laughter) What do you ummm
Do you have anything in particular you would like to talk about before I

P: Well, I think you will know me from discussion in the past that I, as a victim of cancer, would be very interested in, in the subject, in regard to myself. Circumstances have recently arisen whereby I had the misfortune to have what my doctors described to me to be a recurrence of cancer and I have actually gone in the face of the professional advice given me in not having follow up uh radiotherapy. That in itself is a subject which uhh I am happy to discuss with you because I think there are some messages there which uh are worth (.) analysing umm. I didn't disregard my doctors advice easily. Uhh but I have uhh a fairly long history now of uh related illnesses, in fact I've had three illness. Perhaps it would help if I (.) uhh just very briefly go over those three illnesses to define the, the linkage between

R: Yes that would be great.

P: Because uhh, it's very important in analyzing my umm behaviour as it were which uhh was uhh perhaps unexpected in regard to my doctors concerning the latest or the last umm problem of cancer. So let's just go over the, uhh very briefly over the, the history.

R: Background, yes.

P: Right, uhh eight years ago, I had the misfortune to have umm, uhh a diseased testicle and that umm problem uhh was uhh overcome. The, the testicle was removed uh it was, there were no uhh problems relating to that but what is significant about it and what may have linkage with uhh other illness to follow was the fact that my immune system was uh severely uh damaged uh because I had been fighting this problem for some months.

R: Was it damaged by the treatment?

P: No, damaged simply by fighting the diseased testicle. That was my

R: Oh right.

P: view as to what happened and to illustrate the difficulty associated with immunity. I remember
going to hospital uhh to have uhh the testicle removed and feeling how relieved I was to go to hospital because I didn't have to go to work

R: Laughter.

P: I was so tired and exhausted

R: Right.

P: Umm and uhh secondly to illustrate the point uh the doctors at the time uh were contemplating giving me uhh a blood transfusion because my blood quality was so poor

R: Right.

P: and I would measure that personally as being a good indication as to how uhh poor my immune system was at that time. Two years later, I had the misfortune to be diagnosed as being a cancer victim with a tumour on my neck, on my right hand side of my neck umm. This was uh uh removed and radiotherapy was prescribed and taken uh. The problem arising from that particular illness was that umm I understood from your good self that uhh (1) there, there was likely to be a primary, a primary which caused that cancer in my neck and uhh a very thorough uhh investigation arose to find where that primary was located. Huh there were many suspicions of it being in the throat or throatal area and because it wasn't found umm the uh radiotherapy was actually directed uh uh heavily in that area just in case of uh there being a lurking tumour, tumour for want of a better expression umm but nothing was found. So it remained somewhat inconclusive uh although I was told, again by your good self, that umm probably uhh the, there was no primary, it was a spurious outbreak of uh uh uh a cancerous tumour. Uhh I suspected that that might be to help ease my umm, my worries into the immediate future and I still felt some apprehension about there being a primary uh, uh and I think that's understandable in that situation. Uhh and uhh it was also believed that the tumour arose from when my immune system uhh was severely disabled from two years previously because uh the tumour was believed to be in the order of 2 years old when removed and that fitted that particular umm scenario rather well. Now I did carry a worry about there being a primary. And, with justification one should not just walk away and ignore that possibility so I actually undertook a policy of keeping fit

R: Right.

P: uhh in that period and I, I'm now going back of course some six years

R: Uh-huh.

P: and uhh, I did in fact undertake regular until quite recently uhh not great strenuous exercise but measures to try and keep myself fit.
*(I read somewhere, exercise, raising the pulse wuite sharply, may have the effect of preventing cancer cells circulating in the blood from attaching themselves in blood vessel walls. So this exercise was targeted to increase pulse rate specifically-**note added by P when reading transcript)***
Uhh so you can see that I was carrying concern about uh that primary. Now, uhh (.) at the time that this uhh search had been conducted, I did raise uhh with yourself uhh the possibility of it being a cyst which was on my scalp at the time. Uhh this you dismissed as being uhh quite improbable and that uh since since that particular time it had been discarded by doctors also, or disregarded by doctors as being umm uh unlikely and indeed I think three doctors including my own GP uhh uhh stated that (1) his judgement was that it, it would not be the cause or could not be the cause. The degree of umm, of uhh risk factor in that is difficult for me to judge but I came away feeling that it was, it was very improbable, very improbable. However, the cyst uhh had been with me for 20 years uhh and it had been growing progressively (.) uhh and it uhh it played on my mind over the subsequent years uhh. I saw my GP twice in fact, uhh to be reassured that it was not a problem. The second time I was umm, a', anticipating that response and I felt "there's one very easy way of resolving this problem and that is to have it removed" reasoning the need for "cosmetic surgery",

and my doctor, my GP, agreed with that. He indicated to me that the level of priority would be quite low uh but he had a budget to balance and that therefore it wouldn't be immediate. I, I asked just how long it would be and he indicated a couple of months which I thought was not unreasonable to wait. However, that two months extended to six months and I heard nothing from him uhh, and uhh again I worried about the uh the cyst it, it increased to the level where I decided to uhh to go my uhh uhh uhh medical insurance company and seek their approval at having it removed uhh and they agreed. Uhh I was rather doubtful that they would agree because of the nature of it without there being any substance to believe that it was cancerous in any way. They did agree and within two weeks it was removed. Umm and uh I was greatly ha', relieved about that. I felt that whether it was uh a problem or not, it uh was now removed and I could umm uhh relax a little more. Still mindful of that primary uhh but I could relax a little more. It was the only, the only umm aberration as it were on my (.) body that uh uh I could possibly be suspicious of and now it um it had been removed. Uhh you can understand umm that uh, oh I ought to explain that uh umm the doctor who removed the cyst, a Dr B umm believed that the cyst had actually had a life-span of a mere two or three months (1) uhh and this prompted him to actually send the cyst away or to have it examined for possible cancerous tissue and umm, indeed it was cancerous, it was cancerous. Huh, now you can understand, I think, that umm at this moment if we freeze this moment in time uh there was I worrying about a cyst, being reassured by all of my doctors that I had no umm cause to be alarmed about it in any way and suddenly (.) uhh it is cancerous and I'm right. Umm, the uh, the confidence in my doctors at that point in time dropped quite uhh considerably. And that's not to say that I wasn't respectful of my doctors and what they'd done for me uhh but I did feel at that moment. I remember saying to myself "I, be careful here; you're going to have to protect yourself in this situation and be very much involved in the decision making." I think that's a natural reaction for any patient to make. *(Being "right" boosted my sense of willingness to take an independent stance on decision making. That is to say, it gave me a private inner confidence as distinct from a "confrontational" confidence.* ***Note added by P when reading text)***

R: You mean in terms of further treatment and what you've decided to do..

P: Well, well at this time, the, the further treatment really didn't uh, didn't play a part it was simply that umm uhh what had been revealed to me was the uhh, and I was convinced the primary by this time,

R: Mmm.

P: If you, you consider the history and my, my conviction about this umm cyst, you can understand that when it was found to be um uh cancerous, I was less surprised than that doctor

R: Right.

P: uh and uh I felt that it was indicative that uh, uh where the difficulties associated with cancer, it's behaviour the diagnosis etc, that the great difficulties involved in it uh that I should um I should be mindful myself of uh the, those difficulties and the doctors do have limitations in terms of their judgements. Uhh I know it was a broad view which uh I think if you freeze that moment in time you can see was of, of

concern to me.

R: Absolutely.

P: Uh, uh there followed a period which was a little vague to me but umm, clearly uh the question of radiotherapy into the area uh arose which um I should have perhaps anticipated as being a natural uh development having found it to be cancerous but I actually didn't think that because my view was that um, and it fitted perfectly, that this was the primary, it had been sitting on my head now for 20 years and umm (1) it had, it, it, it had been removed at a specific point in time in it's twenty-first year if you like uh and found to be uh uh cancerous and my logic to this was that yes it, it uhh embraced the period when the cancer in my neck occurred. It was logical to me that uhh, with a disabled immune system the window of opportunity had opened and perhaps I was lucky to simply have one tumour arising from it. Huh but that uh you may disagree with, with me on this Richard, I felt that my immune system now healthy and my fitness designed to keep it that way

R: Yes.

P: was enough to (.) keep that primary in check. Uhh, the day it was removed I can assure you absolutely it looked exactly the same as it had done the year before and the year before that

R: Right.

P: and I was confident if it had been left, it would have been on my head a year later looking exactly the same. When I say exactly the same, it was uh growing larger uh progressively but that rate of progression had not changed. Umm, uhh, I think the fact it was growing was one of the factors which lead me to feel very suspicious about it. (1) But there we have a scenario there, we have an interesting situation which I've now created for you and the question of radiotherapy then arose uhh now when that uh, umm was raised, I'd already been through radiotherapy as you well know, I know what it uh, it uh, it does. I know what a brutal form of treatment it is and necessary it is in the right circumstances but, but here I was being asked by my doctors to undergo further radiotherapy treatment in an area where the tumour was, where the cyst had been, now removed of course, the, the bulk of the risk had been taken away and in my view based upon my logic relating to the history of that um cyst was that umm if it had been left it would have continued sitting on my head doing nothing, passive, in a passive state controlled by my immune system. Now that's a non medical man's view (1) based upon me knowing my body and understanding the history in detail. I am very conscious that doctors can not always hold uh that depth of understanding. Many of the things Richard that I've told you about, my earlier cancer I am sure you will have forgotten understandably but I havn't forgotten, I live with it every day virtually. Now, my reaction to this situation being confronted with umm uhh, it, it was absolutely impossible question. Uh, if, if, if I was told, and this is very significant, I was told in a follow up consultation that umm the cancer in the cyst was not related in any way to my previous cancer, it was a spurious development of cancer for the second time

R: Were you?

P: Uhh, now if you, if you put that to one side as, as being, as being a statement uhh and that uhh there uhh was a need to uhh have radiotherapy into the area where the um where the um cyst had been (1) uhh now after that consultation I went home and I was shocked because it wasn't what I expected from my doctor at all. I expected there to be some (.) recognition that I was right, now I, I'm not trying to be (1) suggest that I know better than my doctors here, they may well have had more information to work on that I had and I'm sure they did but it was not a logical outcome for the circumstances that, I'd, I'd defined and uhh uhh it's interesting because umm I think uh, I, I understand trauma a little more now because trauma to me is being in the situation where you have a problem which you can not control uhh yet you wish to take it over and solve it for yourself and I think when umm you're life's at stake, and I'm not suggesting my life was at stake here, in fact, I was, I was arguing for the opposite - not to have radiotherapy treatment, to avoid radiotherapy treatment for two reasons. Uhh it would um take a large piece of my uh, my hair off of my head and umm it's one thing to go bald, it's another to have radiotherapy and have hair removed

*(This was where my definition of trauma, here described, began. What I declined to say directly in the interview was that I saw the "new cancer" diagnosis to be (possibly) a diagnosis of convenience leading to the "need" for radiotherapy providing protection for the doctor as much as for myself. This is where the urge to take control is seeded-**note added by P when reading the text)***

R: Mmm.

P: The difference visually is umm, is (.) quite umm, quite different.

R: Yes.

P: Secondly, uhh and umm I'll come back to the detail on this a little later but secondly uhh it would involve radiation into the uh into the brain. Now this would have been very light I understand uhh but I take the view that any radio, uh radiotherapy, radiation into the, into any part of the body uhh, in order to do good as to do bad as well and when the brain to me a very sensitive organ, it may be a very resilient organ I think but to me it's a very sensitive organ uhh and I wonder (1) uhh and this is, this isn't a, a criticism of doctors here, whether in fact doctors in prescribing uhh radiotherapy (.) uhh whether they truly take into account the long term effects uhh. I think there is a umm uhh a uhh sense of concern about the present and the immediate future

R: Mmm mmm.

P: uhh but the long term future is very much on the back burner and by that I mean there is no statistical indicator to suggest that damage in my case would be very limited. And, I worry about conditions later in life such as uhh Alzheimer's disease or Parkinson's disease which might be brought forward by 6 months or a year or two years arising from uhh radiotherapy into the brain. Now I don't think any doctor could actually uhh, you may uh, you may contradict me here but I, I would doubt whether (.) uhh any statistical evidence uhh could reliably be extracted relating to the umm the advancement of a disease that is impending anyway. Therefore statistically

it would be very difficult to (.) to determine.

R: To illustrate that yes.

P: So that concerned me. It concerned me because I felt that doctors would, do tend to think about present and the immediate future rather than the (.) distant future uh uh uh and again, perhaps I'm wrong. Perhaps I miss judging my doctors here but this concerned me about having radiotherapy. Umm the, the very fact that the umm uhh the uhh cyst was so umm uhh unaffected prior to be removed and it was the same as it had been previously, uhh and it had been removed remember here by chance and found to be cancerous as far as doctors are concerned but I'm concerned with my, with my uhh concept of what had been happening here. It was quite different. I had, I had a story, I had uhh a series of uhh of interlinked events which uhh I was quite happy with. (1) The day I walked out of the uhh con', consultation roo', room, room uhh having seen my doctor and being told of the (.) need for radiotherapy, I went for a long walk.

R: Mmm.

P: I went for a long walk because I always do when something as traumatic as this problem arises in my thoughts, and this is how I've come to understand trauma a little. My thoughts reject everything else, as it were, they were simply put at lower level and my thoughts uhh centred upon uhh the statistical evidence, the, the supposition, the, the uhh sense and feel about this whole uhh enterprise which uhh was about to lead me I felt in the wrong direction and after uh uh uh a couple of hours of walking I found myself able to think very clearly when I go for long walks. Umm I, I, I decided that umm no, I couldn't go ahead with radiotherapy because it wasn't necessary. I had first, I first of all reasoned that umm the probability of getting cancer for the second time was that the odds were so high that umm I found it very difficult to believe. Now I have to be careful with myself here because I'm not a doctor, I can't (.), I can't make judgements upon the possibility of umm, of uhh uhh uhh cancer developing uhh but what I can do is (1) and umm what I did and this took a long time to get round to this my thoughts rolled these problems around endlessly uhh. I decided that I could, I could work out some sort of umm (.) some sort of (.) bad luck factor because I, I'm not a doctor and I decided that uh my bad luck to get uhh cancer for the second time in the period between the age of 55 and 60 (1) uhh, that, that specific period

R: Mmm

P: uhh was in the order of (.) one hundred to one and if you like Richard, I'll tell you how I arrived at it. Ok, I decided uhh that I, I, I felt that I had to be very responsible about this and I wanted to remove any comfort factors that, that one is inclined to build in to steer the argument into umm, uhh into a form that would be uhh acceptable to me. I wanted to be realistic about it. So the first thing I had to do was to get rid of the risk factor because I could, I couldn't deal with the risk factor so I had to relate to umm (.) purely and simply to this bad luck factor. I decided that umm if you were to take uh uh umm, I'll ask you to, to give me your opinion. I decided that if I took a thousand men between the age of 55 and 60 and monitored their health in that period then 10 of them would have some form of cancer, any form of cancer - leukaemia, whatever, uhh quite well removed from uh the, the, the problem that I have but it

seemed that that was the only way to do it

R: Right.

P: to get as wide umm a uhh range of cancer uhh because otherwise I couldn't believe my own figures and I felt ten in a thousand would be

R: I can, I can see how you arrived at (1) two cancers

P: Uhh

R: Is that one in a hundred?

P: Well it uhh uhh, well, well

R: Sorry I don't mean to break into your flow there

P: No, it's very simple, exactly as I put it to you. I imagined the likelihood of cancer associated with that many, many people

R: Right.

P: you know people in the media we know.

R: I see, right.

P: I simply, I extracted the probability of how many would umm uhh fall victim to cancer.

R: Oh I see, ten in a thousand is one in a hundred

P: Between, that's right.

R: Yes.

P: Ok between the age of 55

R: Yes.

P: A thousand, I had to use a thousand because uh

R: Yes.

P: it seemed more pragmatic to do that otherwise if you start getting down to lower figures you distort the figures

R: Yes.

P: so a thousand seemed to be a reasonable number. Uhh now this is pure imagination. You may say to me, absolute nonsense.

R: No, no.

P: Ten in a thousand felt right to me so my first bit of bad luck was that I was the one in a hundred victim of cancer. Then I looked at the tumour, at the umm at the cyst.

R: Right.

P: Now uhh now my argument was (1) that if you take those odds a year before or two years before or 8 years before, that you would have found cancer cells.

R: Mmm mm.

P: Umm and uhh if uhh the diagnosis was correct, then and bear in mind the cyst looked exactly the same the day it came off as, as it had done in previous years, umm I (1) decided that the risk factor sorry not the risk factor the uhh the bad luck factor here if it exists for twenty years would be, and lets take a year that seems reasonable, one year uhh because uhh it might have been active for some little while unknown to me, although it looked the same, and it's surface it's not in the body, it's not invisible in that sense uhh so I decided that the risk factor, sorry not the risk factor the uh the bad luck factor for that would be one in twenty years

R: Alright.

P: twenty to one. I was uhh very tempted to then uhh say well we have two, if the doctors are right, we have two risk factors, sorry, I said it again, two umm bad luck factors uhh a hundred to one and twenty to one and when one is working with umm uhh probability figures uhh one is entitled to multiply the two together

R: Yes.

P: Uhh I felt that was unfair actually because umm uhh I just felt that was unfair and I, I, I didn't do that. If I had of course, the, the uhh the bad, uhh the bad luck factor would have been two thousand to one

R: Yes.

P: Uhh now umm I had now (2) satisfied myself I had tangible figures to relate to I felt and even though they were bad luck figures rather than uhh risk this figure which a doctor would arrive at, I felt comfortable with it and uhh from that moment on, I really felt uhh confident that uhh there was no need for uhh radio (.) therapy and that's only part of the story because of course I had interviews with uhh my cancer specialist.,

Many discussions on the subject of probability of recurrence arose or relating to it. There was the assumption that it was indeed an independent separate umm cancer but I won't go into that at this stage.

R: May, may I explore that with you?

P: Yes by all means.

R: I, I know your background is mathematical and so if we had quite a discussion about probability and I like the way you've handled it umm I mean I can see what you've done but at the same time you use the word "feel right" quite a lot

P: Yes.

R: so it seemed to me that you used, and I don't want to put words into your mouth but I get a sense that you are using the, these intellectual statistical mathematical arguments to, and, and you have trouble getting data but you've used this until you've got a solution that felt right.

P: Yes.

R: Is that right?

P: That's right.

R: Until you were happy?

P: Well I, yes I was, I, I was uncomfortable uhh I couldn't live with the idea of opposing my doctors (.) who were adamant about it being uhh an independence uhh generation of new, a new cancer uhh and in confronting that with umm uh a rather umm broad vague feel factor.

R: Mmm.

P: How can you relate one to the other? Well, there's no contest. I, I, would, I would have had to have taken my doctors opinion. I had to find something that I could uhh I could quantify

R: Mmm.

P: in a way which would uhh give me umm a uhh power if you like, the power to say 'no, I don't think that it's appropriate that I have uhh radiotherapy because I'm confident uhh there's not going to be uhh regeneration. So this, this is still a risky thing for me to do

R: Yes.

P: of course because uhh OK the, the uhh cyst has been removed, perhaps there are cancer cells still lurking in the injury and this was pointed out to me uhh several times by my doctors but I felt (1) that uhh, and this is where I'm now beginning to broach into umm into regions uhh where I'm not qualified to umm express opinion, I felt that my immune system and I've got great confidence in my immune system, uhh would in fact uhh be able to deal with those problems. I'd, I felt that and if, if there was any, any non statistical umm sense of confidence uhh in all that I say it was the belief that my immune system would deal with any (.) cancer cells that might have remained in that injury because I could not put any, any uhh umm bad luck factor or

risk factor or any factor into that but I felt sure (.) uhh there, there was in fact of course the background uhh knowledge that it had looked after the cyst as I saw it for 20 years and therefore the risk was extremely low and I was happy with the figures that I produced.

(Always in my mind were the dire consequences of being wrong, in spite of my firm conviction that this was not a new cancer and, further, my immune system was capable, as it had been for some six years, of preventing further secondary tumours forming.

As I stated earlier my confidence was private and within me rather than confrontational. Before becoming confrontational it was necessary for me to have the opportunity to explain the full case history and present with it my own logical conclusions.

*Regretable, Dr B was not prepared to spend his time listening and as a result I continued to carry my conviction and my worries within myself –**note added by P on reading the text)***

R: You are saying so many interesting things I have trouble keeping them all in my mind, a lot of things I want to ask you but umm and this doesn't directly follow from what you've just said, it just goes back a couple of minutes to a moment when you said you felt powerless umm, in fact, umm to, to do what you felt to be the right thing and (1) I get a sense that what you needed to do was translate the medical knowledge, the information you're getting from the radiotherapy and the general surgeon whom you saw into, into a kind of language that you understood, seemed to be able to make an intuitive decision

P: Yes.

R: that you felt comfortable

P: Yes.

R: with.

P: Yes, well that's,

R: A method of empowering yourself

P: Well yes indeed and I regret very much not asking more questions but umm this is another weakness in, in a doctor patient relationship, particularly with cancer I think.

R: Right.

P: Uhh the contact that uhh (.) a patient has with his specialist is limited to perhaps 20 minutes uhh in a fortnight

R: Very little time.

P: Yes, yes, how umm it is understandable that uhh you may have a list of questions to answer but the asking one question may lead to the generation of further questions to ask and to expect the pat', the patient to actually umm ask all of the right questions to satisfy himself or to understand is very difficult. I never felt that I had the full story. I, I'm sure I, I would have asked umm uhh Dr, Dr B more about why he decided that this was uhh umm uhh a new cancer.

R: Mmm.

P: But I, but I can't remember getting any, any information back but I honestly can't remember asking the questions either umm but I'm sure I would have done uhh, therefore I'm, I really didn't know why (.) uhh he had come to the conclusion that it was a second cancer, other than to say he must have been uhh uhh consistent with my other doctors sure that the uhh cyst on my head could not have generated the new cancer in my neck.

R: Do you, do you get a sense that the system is set up to make it (.) difficult for you to ask questions?

P: I, no don't think that at all. I think, that it, it, it's just a weakness in, in the, there's another point uhh, there are three points which concern me about uhh doctors. Uhh and umm I had thought about these before seeing you because I thought they might come up. Uhh I have raised two of them al', already. Umm uhh one is the uhh is the long term problem

R: Yes.

P: the fact that uhh I, I'm suspicious that my doctors uhh are concerned about the present and the immediate future and I understand that,

R: Yes.

P: I understand that very well uhh but, but there is a long term uhh factor as well and that's of more, more concern to the patient that to the doctor. That concerned me. Uhh and that's an argument for being careful about uhh, umm recommending radiotherapy perhaps but there's another bigger, deeper and more profound problem which is that uh

R: This is the second one?

P: Uhh uhh umm I was coming to the third one actually. The, the second one is, is that uh uh the uhh consultation time that uhh the patient has, the opportunity to, to explore with doctor his full (1) medical condition.

R: Mmm.

P: Uhh that's umm that's very limited and I went away often I accepted it

R: Mmm.

P: and oth', other patients accept it because you, you as a doctor uhh in a, a year for example will see what, a hundred and fifty different patient? Perhaps even more and maybe less that's very uhh conservative but you have to share your time with

R: You may be surprised if I tell you it's more like three or four thousand.

P: Well you have to share your, your three hundred and sixty five days amongst those three or four thousand patients

R: Mmm.

P: uhh many of uhh of whom will have very serious illnesses because of the nature of your the work you're in. Uhh you also have a home life uhh therefore the umm the thinking time that you can give to your patients uhh and the interchange that you can have with your patients is extremely limited. The patient however, has all the time in the world. Not only that, he is traumatised to the point where he excludes all other thought and his thoughts centre on his problem and they roll around the brain endlessly. I know, I've been through it.

R: Right, well I mean, sorry, sorry to interrupt but what I was suggesting to you was that perhaps that is, that is the way the organisation is set up to prevent too great an interchange in discussion with quite difficult emotional issues which might include (1) cancer

P: Yes, that's right.

R: I mean that's certainly emotionally it's not intellectually the xxx thing to do but if your whole day is, is uh like that it can become exhausting and I, I just wondered if you had a sense that the way things are set up is to prevent too deep the discussion.

P: No, no, I, I think I, I, I have to say that of all of my doctors that they, they applied their time and their thoughts in the best way possible to help me.

R: Right.

P: I always felt simply that the number of patients you see, which is far more than I'd realised actually, is so great that your time of necessity has to be shared.

R: But I just, I didn't want to give you a sense of not being umm of being less important because you're part of the greater number

P: No, no.

R: But just the reality of it is

P: Oh yes I understand that, no, I, I have no, no gripes about this. I think, we have how many doctors to the population? One in, I have no idea but one in a thousand is it? I'm not sure.

R: Umm.

P: Fully qualified doctors.

R: In primary it care it's about one in one and a half to two thousand.

P: Yes I'd agree with that. Uhh it is a reality. Uhh it is a reality which I have to accept. I'm not complaining here Richard but it is another weakness.

R: Yes.

P: And, and therefore and the point I'm really coming to is

R: Is this the third one?

P: No, no it's still the second one, you, you're racing ahead of me. No the point that needs to be made about this one, I've already made the point about the umm uhh the, the Alzheimer's disease

R: Yes.

P: and the fact that doctors, I suspect, don't give the consideration to

R: To the long term.

P: That's one factor. This factor is that the doctor is unable to provide this time and thought, due to his work load. It is more likely the patient feels, and I do as a patient, that he has a greater privilege of information than the doctor has

R: Mmm mmm.

P: because of the fact that I have lived with my condition, I have after all been within the body, the diseased body over the protracted period

R: Right.

P: and all those details are at my finger tips, they go round my head so often they are at my finger tips. I can remember everything. My doctor can't. That means that uhh the patient has an advantage, it, a minor advantage, but he has an advantage, which he should use uhh uhh to uhh his best interest. Now uhh

R: Can, can I ask you, you, you say that's medical information that is

P: No, no.

R: sometimes ignored? It's not in the conventional sense.

P: No, I'm referring to the fact that the doctor gets it with the rounded edges not the sharp edges.

R: Ok.

P: And the sharp edges being the detail, the subtlety, the little things which often get missed

R: Right.

(I think this is very important. When a patient raises a point or asks a question, it's asking will contain many motivating elements.
(a) He may be asking a logical question strictly within the framework of the current dialogue.
(b) He may be asking a logical question outside of the current dialogue, relating to matters unknown to his doctor-thought to be too loosely connected perhaps to be worthy of raising with his doctor, or too lengthy to describe, or too complicated to describe
(c) He may be demonstrating an understanding, or lack of understanding, of what may have been previously said.
The point being made here is, in my opinion, there are, in responsive behaviour, clues, which if identified can be more revealing and diagnostically helpful- ***added by P on reading the text)***

P: or not even raised by the patient but are there if you, you had time to probe by asking questions.

R: Do doctors miss those?

P: They miss them but the patient doesn't and if the patient is an aware patient

R: Yes.

P: they're meaningful. If the patient is an unaware patient, they, they're not.

R: The, the reason why I asked the question I have done is that I, umm, very much developed a sense that **(.)** when patients tell you something umm like they instinctively feel like you did that the, the uhh cyst as you called it on your head was a tumour, that whilst that is nothing more or less than a, if you like, a piece of information from, from a patient that is medically unsophisticated

P: Yes.

R: I think it's, I'm beginning to realise that it's important to regard that as a piece of medical information as important as a blood count or, umm an appearance under a microscope. That is actually telling you something because patients have sensors inside giving information about how they work.

P: Well I think that's part of it.

R: Is that really that

P: I think there is that uhh, that umm instinct because that's what we're talking about

really.

R: Yes.

P: It's, it's an instinctive feeling umm but often if you look at instinct, it is related to subliminal thought which is not easy to, to analyse. Umm uhh I remember the other day I was thinking about why was I so convinced about umm it not being necessary for radiotherapy *(coughing)* and I couldn't recall why I was so convinced but really it was based upon uhh real facts or real uhh supposition of events I think such as the uhh the umm bad luck factors.

R: The statistical construction.

P: Yes and, and then eventually and this is umm this is how the mind works as I see it uh all the thought processes were in trauma. They rolled these facts around so many times that eventually you don't have to think about them any more. You carry a sense of conviction but really the conviction is related to the fact that you have uhh uhh analysed all of those, all of that information, all of the subtleties and probabilities if you like uhh and they produce uh uh uh a figure which is your confidence figure and you don't have to relate to it any more

R: Mmm.

P: because I, I found that that's what I did. Initially I rolled all of the facts around in my head, I thought very deeply about them. I went over these, these probability figures, same, same word again uhh

R: I know what you mean.

P: but event', but eventually I didn't have to do it anymore because I, I felt a conviction that was founded upon those earlier thoughts.

R: So you turned, you turned an intellectual, a series of intellectual processes

P: Yes.

R: into a feeling.

P: Well into a, yes, into a sense of confidence

R: Right.

P: which had a value to it which was very positive.

R: Right.

P: Uhh, I, I think you know uhh that you could, you could have a range of **(1)** senses of confidence ranging from nil to ten

R: Yes.

P: and I was around the nine and a half.

R: Right. **(2)** Do you look upon it **(1)** umm I, I think I know what you mean and I, I have umm begun to think that this happens both in myself and in others for quite some time. I look upon it as uhh a dialogue between your umm your sort of intellectual reasoning

P: Yes.

R: and your gut feeling and, and eventually umm

P: I was going to say uhh the gut feeling to me is intellectual reasoning.

R: OK.

P: Uhh but

R: xxx*(unintelligible)*

P: Well I think it's pragmatism. In my case I felt that it was always based upon some sound reasoning, but I am prepared to accept that there are fringes

R: Right.

P: to, to this whereby the unconscious thought plays a part in making contributions uhh and they may be related to subtleties uhh umm some of them almost long forgotten. Richard I'm going to tell you another thing which you umm you will have long forgotten but I haven't and this one of those subtleties, one of the pointers which you knew about at the time, it was a pointer, it was sitting in my mind somewhere, it was positive and helped this umm sense of confidence at the end of the day and it goes back to the uhh, the illness I had with the uhh diseased uhh uhh testicle. At that time, as part of the uhh uhh medication, I was given an antibiotic. Uhh I'll just challenge you to remember that.

R: No I don't.

P: You don't. I wouldn't expect you to.

R: Well I wasn't, I wasn't looking after you in that process.

P: Umm but you were. I had mentioned it to you.

R: Did I?

P: Yes. I'd mentioned it to you and uhh your reaction was umm dismissive of it.

R: Oops.

P: Ok.

R: Right.

P: Umm.

R: You'd been, you'd been given an antibiotic as uhh part of the treatment.

P: I'm going to explain it first of all

R: Yes.

P: and then you'll understand the meaning for this, for me saying this.

R: OK.

P: I, I was given uh an, an antibiotic to help the recovery following the removal of the testicle.

R: Yes.

P: Uhh I was asked beforehand, as one always is, uhh was I, I, did I react to uh antibiotics and any particular antibiotics. I had never reacted to antibiotics before but I did react on this occasion. I had a swelling on the right hand side of my neck uhh

R: mmm

P: not on the left hand side.

R: **xxx***(unintelligible)*

P: Umm if I had swellings on the right-hand and left hand side, I would have dismissed it but it was on the right hand side only, not the left hand side. Now umm I'm not a medical man but I would make a judgement that umm if the gland in the right are effected then the left must also be effected but maybe there are medical reasons to uhh, to uhh discount that but I thought that was very significant uhh

R: Some years later you, your had your tumour there.

P: That's right. That might have been a pointer, an indicator that uhh a tumour was already present at that time. That's what I felt and I explained that to you at the time and umm I was rather surprised that you didn't actually pick this up. Perhaps you did, I mean we're talking body language now uhh and but anyway umm that uhh that hinges back in my memory as being another of those fringe indicators

R: Yes.

P: almost long forgotten but which umm has a small contribution to the overall sense of confidence.

R: Well in, in my defence the idea that an antibiotic would trigger off a reaction in

uhh in a tumour that was to develop some years later umm **(.)** as far as, as far as we know

P: Yes.

R: I mean, you're going back

P: You say as far as you know you see.

R: Yes, yes.

P: Umm.

R: Anyway, that wouldn't fit in with any conventional medical framework and, and that, that's the response I'm giving you. I think umm I'm become, becoming a lit', little less ready to accept conventional

P: Yes.

R: framework.

P: Well OK it's interesting that you say that.

R: I think that I am more open about that now.

P: O, OK it's interesting that you say that. I understand why you say that Richard and I thinks that's uhh why you made that judgement umm all those years ago but you can understand more perhaps recently than then because of my history and, and the, and the outcome of the recent uhh situation. Looking back on it

R: Mmm.

P: I have doubts about whether my doctor at that time was in fact fair in dismissing it uhh, it, which is the opposite of your view now. You're saying well may, maybe, maybe that, that the convention thinking about such matters uhh needs to be looked at umm uhh perhaps umm perhaps in a more detailed way. And I'm saying the opposite to you now

R: Mmm.

P: because of umm of the recent history.

R: Well I'm the product of my own conditioning as well.

P: Yes of course.

R: When when I go to medical school and I'm taught to look at things in a conventional way

P: I understand but I understand that

R: It is very hard to suddenly back off and challenge that.

P: Yes.

R: umm and say well perhaps there are alternative ways of looking at the world that enables you to take the piece of information and fit it into your frame and try to make sense of it.

P: Yes, yes. I'm not trying to drive you into a defensive position on that.

R: You, you can do that if you want. I, I don't mind. You know you can.

P: Umm but I think it's, I mention it

R: Yes.

P: Because we're being frank and because umm I'm, I'm, I'm sure you would like to hear from me not just the obvious but umm the intangible facts in this. Those that are difficult to reach and describe and define.

R: Very much so yes and, and umm can I just make it clear to you that I, I don't want you to feel that you can, you need to censor anything. I'm much more interested in, in hearing what you really have to say without **(1)** uhh you may think it's uncomfortable for me to take, I, I can take that and without there being a sort of sense of filtering things I really want to say this to Richard but I'm I'm not sure that uhh that I want to Richard that much.

P: Right.

R: There's a couple of things where we may get into that.

P: OK, I didn't come into this interview Richard I assure you with uhh with any intention of protecting you from my opinion that might *(laughter).*

R: Alright.

P: I'm sure you wouldn't have reacted unkindly anyway to anything I say.

R: Is this OK then.

P: Yes that's fine.

R: What we have done so far.

P: Yes, no problem at all.

R: You, you said there were three things.

P: Ahh yes, yes.

R: Can I go back to that.

P: Yes we can.

R: Unless there was more you wanted to say about that.

P: No, No, I'll just reiterate to say that one is the concern for old age related to treatment. I think doctors tend to think of the present

R: Sure, yes.

P: and the immediate future. Uhh the second is the limited time that umm the doctor has with his patient in consultation and therefore the communication factor that uhh arises, the poor communication factor, uhh coupled with the fact that the patient knows his body, carries with him umm uhh a greater uhh knowledge of the history of his condition that can be the envy of the doctor because

R: xxx

P: within, in, within that knowledge would be all sorts of clues, subtle clues which will be helpful in the diagnosis. The third one is much more damaging I'm afraid. It is the fact that uhh if you looked at, I now define to you the uhh the bad luck factors which I have uhh uhh umm calculated to help me generate confidence

R: Yes.

P: and I have to umm I have to say this, uhh, when it comes to uhh umm deciding when a doctor decides that umm radiotherapy is appropriate uhh I think it's it normally the decision is obvious because the tumour has been removed radiotherapy is necessary. But there will be the occasion, and my **(1)** case is perhaps a good example where the probability that the, the probability taking into account of all of the medical factors involved essentially, is that the risk of recurrence is low **(1)** and I would ask the question "How can a doctor, no matter how low the risk, not recommend radiotherapy?" because he has to protect himself.

R: Mmm.

P: The protection of himself in this case is of course against a uhh a uhh accusation made perhaps if he were to be wrong uhh and you've mentioned to me that you see uhh three thousand patients a year

R: Mmm.

P: the odds of three thousand to one to me would be odds to take the chance not to have radiotherapy.

R: Sure.

P: but a doctor can't and I suspect and I, I'd put a sharp edge on this that uhh doctors

prescribe radiotherapy not so much for their patients but for themselves.

R: Do you think, do you think they could extend that idea to treatment in general but there's a tendency to try treatment so that you'll

P: Oh yes, I think that's true but I think with cancer the, the, the umm radiotherapy argument is perfect

R: Mmm.

P: example. It illustrates the difficulty between the doctors who, because he doesn't choose to prescribe radiotherapy set against those odds of one in three thousand whatever,

R: Right.

P: will see more than three thousand patients in his lifetime, statistically he is destined for court action against you (him).

R: Do you think it is possible to open that issue up for negotiation?

P: Yes I think so but it, uhh you'll see *(laughter)* this is where I come back to my problem with the umm decision that I had cancer of a different type, spuriously regenerated when so obviously there, there, there, there appeared on the surface to be an association with the previous cancer.

R: Right.

P: That is uhh uhh this is, this is very unfair on you uhh uhh Richard and I'm going to be very unfair. I'm going to say what I, what I think because that's what you want. **(1)** To decide that I had uhh cancer of a, of a new generation, independent of the other, against those long odds, could well be an act of convenience **(1)** because it changes the perspective on uhh whether radiotherapy should be uhh administered or not.

R: What do you mean by that? Could you just elaborate a little?

P: Well OK, if I look logically at my, at my umm uhh cyst which had been sitting there for 20 years.

R: Right.

P: It looked the same as it did the year before, the year before that, and it had been left, I was convinced in my mind, there was statistical evidence that it would have been exactly the same in a year's time as it was being cared for by my immune system. I was being protected by a strong immune system.

R: Mmm mm.

P: And uhh uhh this is not uhh something I'm, I'm constructing uhh simply to level

an argument, I felt that way from uhh the day that uhh you and I parted after umm my earlier

R: Treatment.

P: treatment that's right.

R: On the neck.

P: On the neck, that I, that there could be a primary and that umm I should uhh simply to protect my good health, uhh exercise to maintain a good umm immune system

R: Mmm.

P: to protect me against that possible tumour and that possible tumour, as I now see it, was in fact that cyst and therefore the removal of the cyst would eliminate it. Controlling the possible risk of cancer recurring but it wasn't that it was going to occur anyway because it was being taken care of by my immune system. Uhh there might well have been a time at some point in the lifetime of that cyst when it would reach a point where it would be, if you like, self generative and become a real threat to my, to my health. But why should that suddenly be in it's twenty-first year?

R: Right.

P: That's the argument.

(3)

R: Your, there's **(1)** on the one hand you just proposed there was an argument that doctors do things to cover themselves and I umm actually agree with you and I think that does, that does go on and it's certainly one of the things that needs watching and managing.

P: That's not actually a criticism of doctors, it is the pressures on them that is doing it,

R: And it doesn't come across as a criticism

P: Yes.

R: because you, you, you see uhh umm uhh a kind of rational and practical

P: Yes.

R: explanation

P: Yes.

R: for why people behave like that and I think you're right. It's very, very umm

perceptive of you to pick it up. Umm but at the same time I, you had a cyst that you brought to my attention but I didn't operate on

P: Yes.

R: and, and yet I wasn't, I wasn't covering myself. After all, there are two things about removing that cyst from my point of view. One is that it would be extremely easy for me to do and secondly I would have got paid to do it. Which actually brings out an issue for me because I

P: Excuse me Richard. I think that's a different issue because you were at that time, and I can understand, believing that this was not the source of the cancer and I can understand the medical argument

R: Arguments for it.

P: Yes, were in fact against that being the case, supported by the fact that three other doctors said exactly the same thing with the same conviction so I understand that. Uhh the problem arises when the, when it's removed and it's found to be cancerous then in fact we have to decide uhh why it's cancerous. Is it

R: Yes.

P: associated with the previous cancer? It's always been cancerous and it caused the previous tumour? Or it is another, it is a spurious event which has created a new cancer. So these, these are different analyses as far as treatment is concerned.

R: So what you're saying is that people have decided to go ahead with radiotherapy to cover themselves as it were and therefore they construct an argument

P: That's a terrible thing for me to say.

R: xxx

P: But yes.

R: They construct on argument based around the idea that, that this must have undergone malignant change in the last two or three years

P: It was another factor, another factor which created the envelope of confidence. **(2)** This might have been the case

R: Right.

P: and if it, if it had been the case then my argument uhh relating to the truth of the history of that uhh cancer, would carry and there would be no need for radiotherapy.

R: Right so you, you in other words you were able, am I right in saying, you were able to, to see through the the uhh the constructed world of medical knowledge to see why, why that had been done because you were, you were given a series of arguments

that created a good medical reason for going ahead with radiotherapy but you were able to see that that was a constructed world because doctors were then able to do what they really wanted?

P: Yes.

R: without entertaining other possibilities

P: Yes.

R: because you felt were the genuine ones.

P: Well I thinks that's another arm to this actually which is that radiotherapy, sorry if you had a tumour, **Remove it-radiotherapy**!

R: Yes.

P: That it is a progression without uhh uhh evaluation of circumstances that every, every tumour removed uhh has to be treated with radiotherapy, not quite as literally as that because there, there will be circumstance but there will be that rather cold, dispassionate view of it.

R: Yes.

P: And that umm, it would be chemo, chemotherapy or radiotherapy whichever would be appropriate to apply, without considering the detail that I, that I had gone through.

R: Mmm.

P: Uhh and therefore I think, if you freeze that moment when I was told that there was a separate cancer, how withdrawn I think I would have become as a result of that and why it would drive me into those thought, thought processes to justify why I should disagree with my doctors and I don't disagree with doctors lightly.

R: But, no, but, the, the way you did that, it seems to me, was that you **(.)** saw through the reasoning that was being presented to you

P: Yes.

R: and you decided that, it, that, that the sort of umm the medical world that was being constructed

P: Yes.

R: for you by doctors

P: Yes.

R: was actually not legitimate as far as you saw it.

P: Yes, yes but remember, I also had a very powerful umm uhh nudge in that direction

R: Right.

P: arising from the fact that umm this cyst which my doctors had said was not cancerous, was cancerous.

*(This was the key to giving me confidence in challenging my doctors. Not in an open confrontational way-but enough to say 'no' to radiotherapy-**added by P on reading the text**)*

R: Right.

P: Uhh and, and therefore the umm the uhh opinion of my doctors suddenly became slightly different to the way it had been previously.

R: Well that's what I was going to ask you. What provided you with the impetus to challenge that view ? and, and

P: But, but Richard you're, you're putting it to me as if there are single elements in this. But there are not single elements, they are a collection of different elements. Big elements and small elements which produce a collective picture but if you don't have medical umm knowledge, that's all you can do - put together a picture that represents your situation in the best way umm possible and that's really all I have, I have done and I agonised over that because I haven't had the medical knowledge to counter balance my own uhh argument but in spite of that, I was still prepared to say "No, it would wrong to have radiotherapy". The, the, the evidence that I have uhh constructed, bearing in mind uhh as I was very careful to say to you that I calculated on risk factor, on, on umm on bad luck factor rather than risk factor, all of this uhh was very important, was very important and my thought processes only brought this to a conclusion after rolling it round in my head for an awful long time.

R: Right it, so all these, you, you, you've taken me to task over, not taken me task that's the wrong way to say it, pointed out that it wasn't single factors but it was a collection of factors, it was a pattern,

P: Yes, Yes.

R: if you like.

P: It makes it look as if umm it's without reason.

R: Well I don't see it like that but if you want to amplify that,

P: Well no I, I think uhh I'm well I think that all the decision making, all uhh confidence uhh factors if you like are truly related to reality in some form or another but some times that reality is difficult to, to, to grasp. It's, it's survival, it's, it's it's not physical.

R: Mmm.

P: Uhh and therefore when you try and analyse why you felt so confident, you will never get a clear picture because there will be elements which umm are there which have been steering you but which have not uhh been umm uhh tangible enough even to analyse.

R: Right.

P: I hope that makes sense.

R: Umm **(2)** I, I suspect it's one of those umm ideas that are quite difficult to communicate exactly to somebody else but I, I get a sense that you **(1)** you try and describe it in your own mind as much as you can

P: Yes.

R: and then suddenly the, the, the picture becomes clear umm.

P: Yes but you see, it's a very complicated picture. Let me, me go back to that

R: Yes.

P: Radiotherapy-the antibiotic situation-I wouldn't necessarily recall that as an "item" umm it would be a "plus" in my brain

R: Right.

P: which is tucked away somewhere. It's just a label- it is no longer, no longer associated with the antibiotic, it's just a "plus" and I'm counting on all of the plus's and counting all the minuses

R: Right.

P: and I find that the pluses are greater than the minuses.

R: Right.

P: That's the best way of putting it I think.

R: I'm, I'm getting umm a, a picture of somebody who, and I taking umm I taking you back to the moment when, when David the surgeon said you should have radiotherapy and you were kind of semi-shocked at

P: Yes.

R: that point. So you go away and, and then uhh think about it then you meet Hugh

P: Yes.

R: who reinforces the idea that radiotherapy is appropriate.

P: Yes well I quite agree.

R: So you have a strong body of medical opinion

P: Yes.

R: based on the way doctors see things

P: Yes.

R: suggestive of treatment but you've going away and taken all the various elements of the diseases that you've had, the little plus points

P: Yes.

R: the little minus points and you've constructed an alternative world

P: Yes.

R: that suggests that treatment is inappropriate.

P: Yes.

R: Am I, am I

P: Umm

R: am I on the right track

P: Yes.

R: or

P: Yes but I'll just add to that we're not talking of one more plus against the minus sign, we're talking an overload of plus signs as opposed to minus signs. In other words, in other words this is not marginal, this is, this is uhh

R: Definite,

P: very much yes. And that's important. Uhh I will be, I will be sitting on the fence otherwise it would have to produce an overwhelming number of pluses as opposed to minuses. As, as far as uhh uhh uhh **(1)** Hugh

R: Hugh N.

P: N is concerned, uhh I, I really don't know how you doctors communicate with one another. I know you do a lot of writing of letters to each other

R: Yes.

P: uhh and that worries me because I think umm uhh there is a need to have verbal contact uhh in order to communicate detail uhh and I rather got the impression, and I, and I had nothing to support this, umm I rather got the impression that umm uhh Hugh would have simply taken David's view of the cancer, in, in, in a very broad way

R: Right.

P: and would simply have supported it because David had umm made that decision.

R: Right. **(2)** All right, umm I, I can answer that

P: No, well I don't expect you to, no I don't want an answer to it.

R: I simply don't know.

P: No.

R: Umm **(1)** but we have a situation where, where what you wanted to do in the world that you constructed now conflicts with, with the medical world

P: Yes.

R: that's presented to you. Is that right?

P: Absolutely, yes.

R: So how, how, how does, how do you decided to take one rather than the other?

P: Well it's very difficult you see because it's, it's a question of uhh it's a question of confidence uhh in, in conviction. It's, it's the number of pluses as opposed to minuses.

R: Right.

P: Uhh and umm I mean if you, if you uhh, if you were to have a hundred percent pluses uhh I would thump the table and say "No, you're wrong"

R: Right.

P: but uhh I didn't have one hundred percent pluses, I had enough for me to say "I think it would be wrong for me to have uhh radiotherapy". There are other factors in this which umm I havn't gone into. For instance when I spoke to uhh Doctor N, he gave me umm uhh he told me that uhh because it's of a surface nature, uhh he will be able to, to detect the recurrence of umm tumours uhh within a period of two to three months.

R: Right, very easily.

P: Right uhh now umm that's actually important because if you remember, when I did my umm my umm bad luck factor on that, I used a year

R: Right.

P: uhh I used a year because umm I didn't want to build in any comfort factors uhh to, to falsify the situation to my own advantage

R: Right.

P: so I, I always try to err against myself to be sure. Now that actually helps to uhh

R: Because you're more confident.

P: yes, to, to create a great confidence. If, if I hadn't done that, I would have again you know, I would have **(.)** doubted my own figures. I had to do that. I readjusted the figures many times, as you can imagine, until I, I felt that I was well inside the uhh, the umm the margins.

R: Did you, did you reach a moment when suddenly it was the right thing to do? Do you remember that?

P: Uhh.

R: And if so,

P: Well I, I had to uhh I, yes I did, I, I walked for two hours after seeing Doctor umm Doctor B when he first told me

R: And that was before you saw Hugh N.

P: That was before I saw Hugh but uhh the need for radiotherapy was then **(1)** as it were, on the cards uhh and umm after rolling it around my head, of course I already knew that the cancer cells had been found, you appreciate, this was, this was a, a follow up umm consultation. Uhh after walking for two hours, yes I came up with a decision not to. I have to say this Richard as well. Uhh I, I rolled those facts through my head many times uhh and often after consultations with uhh Doctor B and Doctor N because they, uhh I had frequent consultations with them into the recovery period uhh and umm every time I walked away uhh my confidence was hit but within an hour of rolling those facts around

R: **xxx***(unintelligible)*

P: not just that, even stronger, I even felt stronger than that. Yes.

R: So when you, when you interacted again with that medical world

P: Yes.

R: which was giving you **(2)** huhh quite a compellingly different view

P: Yes.

R: uhh we might, might at some point talk about that, you it, it challenged the world that you constructed

P: Yes.

R: for yourself.

P: Yes, my world being based upon logic

R: Yes.

P: I understand that and probability uhh relating to a cyst which had been sitting on my head for twenty years and that, that's the crux of the matter. It doesn't really matter about the umm about whether it, it, it is related uhh cancer or not if you, if you and dis', dismiss that if you wish uhh, it was the same as it was uhh the day it was removed uhh uhh as it was a, a year before and two years before and the probability of it suddenly becoming a threat to me **(.)** uhh seems very unlikely. But that's just one single element, there are many other elements.

*(This is misleading. It was important to me that the evidence supported the view that this was not a new cancer. The cysts appearance in remaining unchanged strongly supported the "primary" theory to me-**added by P on reading the text)***

Coffee delivered.

R: I wanted, I wanted to ask you if this interview was what you expected?

P: Uhh I, I rather hoped it would be like this. Uhh I thought perhaps it would be uhh you ask the questions and me responding largely with yes's and no's and uhh I, I felt that I was not being able to get over to you all of those subtleties which umm which are built into the interchange that happily we've had so far. Umm because otherwise umm you have to remain on umm gener', generalities. Whereas the truth is actually detailed and uhh and the subtleties of uhh of uhh understanding and how could I possibly convince you uhh without going into those details such as the, the uhh uhh the antibiotic uhh situation that arose which was very meaningful to me and I, I was surprised, as I've said, that umm that it wasn't to you uhh but then I often found that with, with many points that I might raise in, in consultation with doctors that uhh where I thought I was saying something significant umm it proved not to be from the doctors point of view uhh but, uhh, uhh and of course I hold it as being important and that's the difference. Uhh I might be uhh I might be uhh swayed by a doctor picking up a point that I thought was quite important and would mean something to me as a result of this reaction to it umm but I would still hold the umm the views that I held about importance which my doctor might not have.

R: Can I respond to that?

P: Yes.

R: Because I think you are, you are taught to look at medical problems in a very particular way

P: Yes.

R: and if the information that comes across doesn't immediately fit into the slot that says "I need this kind of information there" there is an inclination to disregard it.

P: Yes.

R: And part of that is the time thing. The average consultation is actually 7 minutes which is not a lot of time for somebody to come into the room, be seen and discussion of the problem, discussion of treatment options, little bits of kind of socialising, bye bye. All of that has to be done within 7 minutes.

P: Right.

R: I suppose in a way you could argue that you only have time to look at one view.

]**P:** Yes.

R: Can I, can I take you right back to the beginning on this?

P: Yes of course.

R: It was a question of when you were describing your, your story you uhh came in with a striking phrase and, and I would like to just freeze that moment in time and a lot of the discussion we've had subsequently has been around that. I, I am struck by how many different doctors you've seen, many of which, including myself, have failed to take seriously the problem. So I wanted to ask you, what your, your feelings were towards the doctors at that point and that includes me.

P: Well I had tried, I did try to, to give you a uhh a view on that

R: Yes.

P: my confidence in doctors at that point was affected.

R: Yes I've got that but I, I wondered whether or not uhh I slightly sense that you're holding back because I, I would have been quite angry actually I think.

P: No, uhh I've never felt angry about it because I have always felt that the, the doctors have always, all my doctors have given every impression that they have worked very hard to assist me. Uhh uhh that's every doctor umm and that I have reason to be grateful to them for, for a variety of reasons. I wouldn't, I wouldn't therefore generate anger in uhh that situation at all. Actually it's not in my character to actually

R: Right.

P: I, I can't, I'm, I, uhh I find it difficult to get angry, I have to pretend to be angry. It's the only way that I can umm I can uhh often as it were uhh secure the reaction I want. Because getting angry, it's not in my nature to be, no umm I'm genuine about this. I, I felt no **(.)** anger towards any doctor towards that. The nearest I would have got to being resentful to doctors was certainly hearing that umm uhh this was a separate generation of cancer.

*(Resentful because this seemed against the odds, so unlikely. I never secured an understanding of how this was arrived at as it was put to me as a statement of fact. With Dr B such matters were not negotiable. "He was the driver-I was the passenger," best describes all his consultations-**added by P on reading the text)***

R: Rather than a confirmation of the previous..

P: That, that's right. You see, I couldn't be angry about that because I couldn't be sure. My, my doctor might well have been right I just felt strongly that he was not but, but I, I couldn't get angry on something that might prove to be true.

R: Did you feel angry with yourself for not advancing your own belief system

P: Uhh well.

R: more forcefully.

P: Well, that does raise the question, I have to say that with Doctor B I was particularly disappointed. My last consultation with him was very uncomfortable and this was six months down the road into the recovery period. I haven't mentioned this part-having had the cyst removed and deciding not to have radiotherapy, I agreed with Doctor N, who also believed that I should have radiotherapy, and maintained that view until very late into, into the recovery period. Uhh I umm **(1)** having uhh spoken to him in detail, sorry I've lost my thread for a moment here.
Uhh let me recover that.

P: I've just lost it completely I'm afraid (*laughter.*)

R: To put you on track, I was asking you about whether you felt angry with yourself

P: Yes.

R: a lot.

P: I, no, I, I

R: For not advancing your own.

P: No, umm actually I'd moved on from that umm and uhh I was describing wasn't I I think the umm

R: Yes.

P: Yes I was about to, until I lost my way, I was about to tell you that umm during the early period of umm of uhh recovery after surgery, umm **(1)** I uhh **(1)** I was told uhh, gosh I've lost it again, I don't know why I've done that, umm forgive me I'm sorry

R: That's O.K.

P: What was I going to say was that in the early stages the injury failed to recover and

R: You mean when, umm the incision.

P: Yes that's right.

R: That's right.

P: That's right. It uhh a scab formed and I was very sensitive about it. Umm I uhh I, I left it, I didn't touch it. I was very meticulous about that uhh and umm it tended to weep and uhh because of course it forms a scab in it's own right

R: Mmm.

P: it got larger and larger and my first uhh, I can't quite remember why, but my first uhh contact with uhh uhh may, maybe it wasn't my first contact with uhh Doctor Newman but umm I remember seeing, seeing him at the three month point which would have been in January, January 1996 after the, the cyst was removed in umm September 1995 umm but he removed the umm uhh the scab as it formed, which had been there since uhh uhh the umm cyst had been removed and it was full of pus. **(1)** And it hadn't healed at all. And uhh he warned me that this could be an indication that umm uhh there were uhh cancer cells present uhh. That umm **(2)** that worried me to the point where I decided that I had lost the battle, that I was wrong and that I should indeed have radiotherapy.

R: Mmm. A big minus had appeared.

P: A big minus Richard, wiped out all of those plus signs (*laughter)* I'm afraid. Uhh so

R: Can I say you're an electrician? I don't mean you're electrical but, but

P: Yes.

R: sorry an Electrical Engineer.

P: Yes.

R: it's interesting you use plus and minus signs.

P: I suppose yes I understand you picking that up.

R: Yes.

P: So I actually agreed to have radiotherapy. That's important because I think you have to see another dimension of me here - because I was willing to respond and umm react to a situation that was going against me.

R: Mmm mm.

P: Uhh you havn't actually raised the religious factor here which does surprise me because uhh there is the, the blind belief factor which many people carry, **(1)** particularly when uhh their health uhh, is, is seriously threatened, life is threatened.

R: Mmm mm.

P: Uhh **(1)** I could throughout all of this have had the view that umm I was being protected by the good Lord uhh o', on a bind, blind belief. Let me just dispel that, I don't believe in God uhh and umm I have no hangups about that whatsoever. Uhh I am a pragmatic person, uhh and I think you will know from what I've said that uhh all I have put together had been based upon pragmatism so there is, there is no religious, no, no blind belief element in this at all. Hence uhh, it was, it was umm easy for me to make the decision to have radiotherapy wasn't what I wanted to make but I decided that uhh I had lost uhh the, there was no way back **(1)** uhh the argument was clear uhh so I agreed to have radiotherapy. **(2)** And interestingly **(3)** the, the, the injury, was cleaned, it was uhh redressed and uhh the time it takes to arrange radiotherapy is uhh about umm or was for me about twenty days and uhh two days, I had warnings before this mind you, but two days before this radiotherapy, uhh the scab was coming off and there was uhh every indication of healthy skin beneath. **(1)** I cancelled radiotherapy, I contacted Doctor N and asked for uhh an urgent consultation with him and uhh as a result of that we resumed our uhh agreement that he would see me on a regular basis and I wouldn't have radiotherapy. So I was within two days of radiotherapy - it makes an interesting story doesn't it?.

R: Do you think that the two are connected, the decision to go ahead and the fact that it suddenly?

P: No, no I don't think so at all. I think that the, the amount of pus inside, I have thought about that since by the way and I have wondered whether in fact there were cancer cells present and they were wiped out by my immune system as far as I'm concerned if they were

R: And that's what the pus was, that's what the pus was - the immune system working.

P: Is that your professional view?

R: Uhh no, not necessarily.

P: Hold on, you, you, you're putting words into my mouth. No, I **(1)** I didn't think about that because umm no it never occurred to me that that might be the case. I simply felt that the amount of pus there uhh was inhibiting the, the umm the healing process.

R: Ah right, yes.

P: Nothing more than that and umm **(1)** I was delighted when, of course, when uhh the healing process revealed itself because I was back on course and all my arguments had uhh had been justified and that really was the turning point I suppose, if I were to look back honestly. Umm but the reason why I mention it to you is because I want you to realise that umm uhh I wasn't being umm I wasn't blind to radiotherapy uhh I was open to the arguments if they were strong enough.

R: Yes, Yes, the system was still flexible.

P: Uhh yes and therefore if the argument had been strong enough in the beginning, I would have had radiotherapy, against all of the *(coughing)* uhh structures of uhh of reasoning which I put together. Uhh I think that's an interesting point. I think I've come to the end of that uhh of that uhh.

R: I'm, I'm aware that I'm largely asking you questions

P: Yes.

R: and uhh umm and I've very much enjoying it, the answers in this sort of dilemma. Is there anything uhh **(2)** you want to change that a bit, and ask me some questions?

P: *(coughing)* Well not at all Richard. I think the, the story is with me rather than with you umm and what uhh has been said has uhh prompted from me uhh the sort of umm criticism if you like that I would uhh I would wish to umm level uhh in these exceptional circumstances.

R: Right.

P: Uhh these things would never be said to you under normal circumstances. It is because we are sitting down being honest with each other and you are asking me to tell you my true feeling, my honest feelings about uhh my uhh recent history and because I think I have something interesting to say to you and my motivation that I think is that perhaps there is something to be, to be learnt from it. Uhh I, I worry particularly about the many people who may be walking around today who, who have had radiotherapy for example

R: Mmm mm.

P: and umm who are saying to their friends "What a marvellous doctor I've got and radiotherapy is wonderful" when in fact if they hadn't had radiotherapy they would be just as healthy.

R: Right. **(1)** How do you think you got **(.)** to the point where we can talk so

openly?

P: Why we can speak so candidly? Well I think there's uhh, there is a very obvious uhh umm answer for me on that and that is because umm our relationship goes back uhh six years uneventfully. You've not been in the picture over the uhh the recent problem with the cyst.

R: Mmm.

P: Although you have a relationship to it because umm it was there and it was considered at the time, that's as far as your involvement with my recent problems uhh go and uhh as far as my relationship with you is concerned, I really have no **(1)** no uhh problems because umm at the time that you treated me, the decisions you made uhh I accepted. I had no complaints or objections in fundamental terms in what you recommended for me

R: Right.

P: and therefore you, you, you occupy a special place if you like. Umm also I remember very well that uhh when I first had cancer, the day will never be forgotten. I umm I, it's long forgotten as far as you're concerned but uhh you told me, you told me the truth, the absolute truth. I umm I uhh you asked me about that later. I said to you **(2)** I thought you were too brutal to me to give me the truth in that particular way but you were right. It established an honesty and understanding between us which umm I think, uhh has been very important to me.

R: Mmm.

P: More important during the treatment you gave me of course but now I reflect upton that and I feel that I can speak easily to you on such matters.

R: Yes. **(2)** Yes umm it is tricky because it does feel, it does feel brutal to, to be honest and I, I use the word cancer and explain that that's what you've got and I try and do it quite quickly actually. I try and do it within a minute or so

P: Yes.

R: because otherwise you get into a dynamic of uncertainty and people are not really sure what's going to happen because that bit has to be, be quite kind of punchy, quite, very clear. In the interests of being clear has got to be precise and quite clear but it does feel brutal. But I, I have learnt that it immediately produces a climate of honesty because later on, as is the case with most of the people you encounter when they are cured, they believe you although it has a little sting in the tale as far as you're concerned, is that, when, when you are discharged and you've finished treatment, the level of honesty goes into the bit that follows and people actually continue to believe you.

P: Yes.

R: And if you've beaten around the bush from the word go and been unsure and

cagey about the worst of the news, they are very uncertain about whether or not they have been cured. Although it's things that you have said make me wonder whether or not that is the case because **(2)** you, you have on a number of occasions pointed out how **(1)** it's with you all the time. It's milling around in your head.

P: It was, it's not now.

R: Oh right, right, yes you feel free now.

P: Oh yes, yes. Trauma is like that as far as I'm concerned. My definition of trauma is uhh that you have an insoluble problem with uhh, of umm uhh great severity to you

R: Mmm.

P: and uhh the degree of that trauma relates to the umm the uhh exclusion of other thoughts directly related to that uhh and uhh it was quite normal I, I felt, for me to roll those facts around but this is, this is part of the self preservation umm uhh inbuilt uhh instinct in us I, I, I would suggest

R: Yes.

P: that when our lives are threatened, we take control. And that's very interesting actually Richard, because umm I thought about this the other day uhh. It might be just interesting to reveal how I feel

R: Mmm.

P: about uhh an injury. If I were uhh to go into hospital with a broken leg

R: Mmm.

P: umm I wouldn't ask very much of the doctor. I would probably just say "well when will I be up and about again, uhh when can I walk?" and umm " is it going to be very painful" uhh and that would be the end of it. I would wait patiently for the uhh leg to repair and I'd be away. If however it was uhh gangrenous, is that the term?

R: Gangrenous.

P: Gangrenous uhh then I would say "well doctor, how many legs have you repaired like this? I mean, are you proposing to take it off? If you are, why are you going to take it of or if you're not going to take it off, why have you chosen to leave it on"? and, and uhh questions of that type. If however, it, it, it became gangrenous to, to threaten my life, I would say "doctor I want to take over, I want to make the decisions, I couldn't take the decisions". But I'm talking about instinct here, not reality. I'm talking about instinct. I would want to take over

R: Right.

P: because it's my life that's at stake and at the end of the day, I think we all feel like that. Uhh yes can trust uhh umm the doctor, you can trust whoever you like but if it's

your life at stake you can only trust one person and that's yourself.

R: Right.

P: That's, that's a, a, that's an instinct uhh uhh I'm referring too, not uhh the reality that we have to face in life and that's where trauma comes from. It comes from the fact that we can't uhh always control our situation and if there are no answers, trauma is, is, is simply exacerbated.

R: Yes, I umm, I would although I, I have got the wrong end of the stick in some ways umm from my own view because you've given me uhh two or three scenarios in which you demonstrate that there are shifts between uhh as far as decision making is concerned between the patient and the doctor

P: Yes, yes.

R: in, in dramatic ways. I, I was under the impression that when, when your life is threatened with say meningitis or umm peritonitis or something like that, that people would umm would feel very happy for the doctor to take control in a situation where they feel very uncomfortable and uncertain and say umm "you take over" and that's, that's the sort of model I have in my own mind but you are challenging that.

P: You're talking despair doctor.

R: Right.

P: You're not talking uhh **(2)** I think once you've gone through the trauma and realisation that you can't do

R: Right.

P: you can't solve the problem then, then you, then you fall back on despair and it, that's when your doctor surely umm uhh is allowed to take over because there's nothing else left. **(2)** I think there's a difference.

R: Could you elaborate that a bit more?

*(This part of the text covering trauma and despair is at best misleading and is certainly not explored in enough depth here to clarify the contradictions which are arising-**added by P on reading the text**)*

P: Yes, I, I will try and do so as long as there is hope and uhh but the possibility of salvaging the situation, saving you or I

R: Yes.

P: and you want to take charge

R: Right.

P: but if you reach the point where it is lost, then you are in distinct despair and I think then you can only rely on others and that's a mental state I think.

R: Mmm.

P: Uhh I think that's uhh, not sure if that's a clear definition but umm.

R: I think what you're saying is clear to me but I am also thinking that in a way, neither of us have ever reached that point

P: Yes

R: of despair.

P: I've perhaps been closer than you on this.

R: Um uhh yes, what, what made you call me doctor suddenly?

P: I don't know, I don't know actually. I really don't know. Umm, **(1)** no I don't have an answer to that. I suppose it is because when I refer to you, (I rarely talk about what happened to me outside of my home) I refer to you as, as Doctor Canter rather than Richard.

R: Right.

P: I think that's it is just a throwback to that and I picked it up once you see and I did it again

R: Yes, yes, I think you picked it up as an expression

P: Yes.

R: Uhh despair

P: Yes

P: Yes, yes.

R: OK umm **(3)** I'm, I'm lost now. Oh yes, yes, you, you've been closer to despair

P: Yes.

R: than I have.

P: Yes, yes.

R: So you've got, you've got some insight. Is there anything you want to add?

P: Umm **(2)** I would say just to complete my story

R: Mmm.

P: uhh the uhh the healing process then continued. Having been within two days of radiotherapy. I look back, I look back uhh uhh at that you know, aghast uhh I was so close to uhh that commitment into radiotherapy. I would be sitting here now under the camera with a, a very large and prominent bald area here had that been the case and I would, I've said, uhh be worried about uhh the long-term future

R: Mmm. Mmm.

P: and perhaps if I'm destined to have Parkinson's disease it would be advanced. Uhh **(1)** my uhh **(1)** visits to see Dr N now continued uhh and uhh **(3)** he remained concerned about umm uhh me not having radiotherapy. He actually uhh agreed with me uhh negotiated with me even uhh that uhh he, he wished to take samples from the area and have them tested for umm uhh cancer cells on condition that I would have radiotherapy if he found any. We're now six months down the road, the cyst has been removed six months, that [the test] was carried out and I was confident there would be none because the healing process was also umm uhh advanced. There were other difficulties that arose, there was, there was bio', biological contamination which umm uhh caused uhh a hiccup and in fact the final scab wasn't removed until 15 months after the cyst had been removed, a very worrying time for me throughout that uhh. My cyst was in my mind **(.)** very nearly all the time. How I managed to do a day's work, I'm sure I've no idea but umm

R: No.

P: because I did constantly think; "have I made a mistake here? Am I deluding myself?" But if I went back through these arguments, I came out with a very positive feeling about them.

R: So that's evolved, that got stronger as time

P: Well it did yes umm and eventually as I've mentioned to you, I, I didn't do that. The, the, the collective umm confidence factor had detached itself from those figures and, and I, I just carried the

R: The confidence.

P: the confidence. Yes. I think that's important because uhh **(1)** there is a tendency to think that confidence is just based upon some background umm uhh umm **(2)** hope or sense when really it is based upon real judgements

R: Mmm.

P: uhh and allowing for those fringe things which play an important part but add to the pluses or minuses whichever the case may be.

R: When I, when I sort of reflect on what you've said about, about **(1)** taking umm points of the history that the patients may regard as important and doctors perhaps don't, I, I find myself wondering how a doctor **(1)** juggles and certainly, this is, this is

what I find in my own practice **(1)** being authoritative and expert and knowledgeable and somehow communicating that but at the same time being collaborative and taking **(1)** umm notice of what patients say. In umm, and in fact there is this particular comment you made about Hugh N following what somebody else said.

P: Yes.

R: I, I do regard Hugh as actually being a very, very umm kind of collaborative consultative umm doctor

P: Yes.

R: and maybe he could tell you a bit more about that

P: Right.

R: I, I,

P: Can I just elaborate on that?

R: Yes.

P: Because umm I, I wouldn't uhh, I wouldn't level this as a criticism of Doctor N, it is the system I'm, I'm referring to. That's why I made reference to better communication.

R: Yes, yes.

P: Uhh that isn't good enough uhh it uhh words on paper can say so little. You would have to write long letters to uhh, to even cover the uhh the salient points about a umm a uhh diagnosis if you like.

R: Yes.

P: And therefore it would not surprise me if the system was such that Doctor N's reaction to treatment, or perhaps his conclusion as far as treatment is concerned, was simply based upon the information passed to him from the specialist doctor.

*(This is what I believed and it discouraged me from discussing in full detail my inner convictions about the need for radiotherapy with Dr N. I think I regret that now- but please remember I had the cooperation of Dr N and this was progressing to my satisfaction, namely that radiotherapy was in suspension. Only whewn it became evident that radiotherapy was not necessary, did I openly conradict the view that this was a new cancer to Dr N. Dr B had, at this time, no further involvement as far as I was aware- the last consultation with him had been six months before-**added by P on reading the text**)*

R: Mmm.

P: May I ask a question? Do you actually talk to other doctors?

I mean uhh uhh there's obviously a social level but do you, do you have conferences where you talk about your patients?

R: Yes.

P: You do.

R: Yes. Umm either formally in, in multi-disciplinary Head and Neck Clinics when the, there is a problem. Whereas in your case, umm from a conventional medical point of view, treatment has been clearly very straightforward but sometimes uhh there are situations where there are a number of alternatives that are availiable which is the most appropriate way forward but I think a great deal of informative, informal discussion takes place at coffee, in theatre, over lunch about cases that are bothering you . So the, the sort of thinking all the time about a problem that you describe about yourself, takes place umm, as a doctor I feel, with patients who are not straight forward. Especially, especially if things are going wrong so that the same model of trauma that you look describe, I recognise. Things have gone wrong and you find yourself thinking about them all the time and that will involve running it past others to get a general view; it is part of the mutual support system.

P: Do you ever disagree?

R: Oh yes.

P: And how do you deal with umm a umm a treatment when you are in disagreement?**(2)**

R: Well there's some, a disagreement as I see it which may be genuine or artificial, you may ask artificially disagree with somebody to generate a more interesting argument so one doctor will find themselves adopting a view just to really uhh to, to draw the argument out

P: Yes.

R: to make sure that all the issues are stored.

P: But is there a mechanism when you are in disagreement

R: Mmm.

P: for uhh resolving that through a third party if you like which would be a logical thing. If I was organising umm a umm a uhh hospital

R: Yes.

P: with multi uhh specialist uhh officials involved, I would uhh wish to do that because at the end of the say, if two people are in disagreement uhh it, it clearly calls for a third party uhh at least one third party to uhh uhh polarise the decision.

R: It's often the patient, the patient may be presented with **(2)** with uhh alternative

views and say that these are two alternative views.

P: That's dreadful to put to a patient because that just leads to trauma. You surprise me.

R: Umm the, the patients are very happy to go down that aisle. They do recognise that no particular perspective

P: Mmm mm.

R: is uhh is clear but **(1)** those kind of disagreements often arise out of judgements about what, what kind of outcome is acceptable. For example if you have a tumour of the throat you may have a judgement to make about one form of treatment which will give you a higher chance of cure but leaves you without the voice box versus the other

P: I understand, I

R: course of treatment that gives you a small chance of recovery but you keep your voice box.

P: That's slightly different to what, to what I thought would happen.

R: I know.

P: I know what you're saying here is uhh the risks uhh the consequence, the consequence of umm this surgery as opposed to that surgery is that you will loose your voice box or whatever.

R: Yes.

P: Now that's, that's not quite the same thing as what I'm referring to. It's where you have umm uhh uhh a disagreement as to the nature of the problem uhh surely there is a higher authority as it were or a third party

R: Oh yes.

P: to take your umm your, your uhh umm your individual opinions too.

R: That's surprisingly uncommon actually.

P: Oh is it.

R: Yes, which may itself be worrying perhaps there should be more views around and that's generally resolved by further opinion from a major centre.

P: It is, yes, yes.

R: from a major centre.

P: But would be on a, on a, on a casual basis rather than a formal basis?

R: Well, it, it, may be formally referred or informally.

P: And how would that be triggered then? If you were in dispute with another doctor, would you, would you say I can not agree with you. I, this must be taken to a higher authority. Is that how it's done?

R: Umm it's never actually happened to me umm personally but what I would do is make it clear to the patient that there is umm a difference of opinion as to what the most appropriate way forward is here and that in order to, to help we would, we would suggest referral to another centre umm to get uhh, an alternative perspective.

P: Right.

R: I, sus', I guess, I mean I haven't **(1)** I've never really encountered that, it's surprisingly uncommon. That may as I say come as a surprise to you and it, it, I suspect it probably arises out of personal disagreements and personal dislikes that have got in the way of professional advice. What you're looking at is a dispute over who's got the bigger car or who's got the bigger house.

P: Really.

R: Yes

P: That would please no patient, I'm sure.

R: No, I, I mean but I hope mercifully they are uncommon but I suspect that that's kind of outside baggage getting in the way.

P: Right. One thing I haven't uhh spoken of uhh although you alluded to it a little earlier is my, my background. I, I am uhh an Electrical Engineer, I've been an Electrical Engineer uhh pretty well all of my life. I, I had the good fortune to be a creative Electrical Engineer uhh which has made life very interesting for me.

R: Right.

P: And uhh it's interesting because I remember, as uhh, there is a parallel between diagnosing the uhh the faults of complex machinery and uhh with uhh uhh diagnosing human problems, illnesses, uhh at least I think so. Umm machines nowadays are very complex umm uhh the machine I've been working on recently as no less than a thousand sensors and umm a hundred prime movers and valves etc etc. The whole in computer control is a very complex entity. In my early days I used to make mistakes if machines failed

R: Yes.

P: by gathering all of the diagnostic information, and of course the good practice is to take everything, take every scrap of information you can.

R: Yes.

P: Many of these machines umm are so expensive and are so important umm uhh in their operation, they can't be stopped. They have to be repaired on uhh a basis of understanding what to repair.

R: Mmm.

P: Therefore diagnosing problems can be uhh very uhh very important, very serious undertaking and I can remember in my early days, I used to take these facts uhh and I'd look at them *(coughing)* I would umm I would tend to take the primary symptoms uhh and ignore the secondary symptoms and I would come to conclusion uhh and uhh the machine would be stopped and I would investigate and I would find I was wrong uhh and the machine would be uhh inoperative for an unnecessarily long time whilst the real fault was found and put right. I'd then look back at the diagnostic information and I'd find that those details would fit perfectly and if I had not ignored them because they were not mainstream to the problem, I would have put my finger on precisely the problem. **(2)** In later life, I've learnt to do that, not to make those judgements. But I noticed that in younger engineers, they still do it. And it's very interesting because there are occasions when I've looked at the facts and uhh I think of the detail and I uhh I see the complete picture and whenever that happens I've always been absolutely right. Uhh now I think that umm that training as it were, has been helpful in umm the uhh definitions when I've, I've given you

R: Yes, yes.

P: applying to my medical condition.

*(Here the importance of detail is being exposed. It may be this detail, which changes probability into certainty (or probability into improbability) whether in a machine or in the diagnosis of human illness-**added by P on reading the text**)*

R: I, I'm, I can immediately draw parallels with that model and the way you have reacted in a, in a couple of ways but uhh it seems to me that perhaps the strongest point to be made is that is has enabled you to challenge the nature of being an expert. Is, am I right?

P: Yes that's correct. That is right.

R: Yes.

P: That's helped me more in the face of opposition because there have been times

R: Yes.

P: when I've done this and it's very rare this actually happens

R: Yes.

P: because usually you do find the problem very quickly. And of course there is the

danger, if you look at the primary evidence rather than all the evidence

R: Yes.

P: On the occasions when I have spotted the problem from looking at all of the facts, I've gone back to the other engineers that I've had along with me and been absolutely sure that I've been right, enough to over-ride them and if you like, to take a very arrogant stance on the, on the matter

R: Mmm.

P: which I wouldn't do I mean unless I was absolutely sure, always absolutely right.

R: So you, you challenge one belief system after you have...

P: But, it, one, one would only do that if one was absolutely sure.

R: Yes.

P: uhh and there is certainty in certain circumstances, it doesn't happen very often of course but umm occasionally it does. Now I'm sure it does marry with the uhh with saying the diagnostic judgements which uhh, which you have to make. And it brings me back to the patient again

R: Mmm.

P: who has that detailed knowledge and all those subtleties which he carries that umm may seem too peripheral to uhh be uhh important but which add that little details that umm can be the difference between being right or being wrong.

R: Your own experience taught you that that works.

P: Yes.

R: You said you are a pragmatic man and therefore you've been able to translate that into **(1)** into uhh, into your medical

P: Yes.

R: experience.

P: Yes.

R: You, you made the point earlier on about the fact that you weren't religious. Were you, were you religious or do you have a religious background?

P: I uhh, I uhh, I, yes. That is to say, my parents were always God fearing and uhh yes, I went to Sunday School and I think I was about 18 before I decided that umm no this, this world is a random world and that umm I, there are no advantages, there's no purpose. Life is life we have evolved. I, I accept that umm there are questions that I

can't answer but I don't attempt to and I agree that people try to answer the unanswerable and I think that's being pragmatic again. It's umm it's looking at the uhh the reality and making judgements and avoiding making judgements where there isn't evidence to make judgements.

R: Mmm.

P: That's how I view in a handful of words, the world I live in.

R: OK. Do you have a sense that we're slightly running out of steam on the discussion?

P: I think we're coming to the end of the body of uhh what we're saying. We're now down to peripheral matters. It's uhh really with you Richard if you wish to uhh continue or **(2)**

R: Well I, I umm, yes. I don't want to exhaust the process. I was umm, I was going to ask you, a couple of points had occurred to me. We, we mentioned names on the films of a couple of other doctors

P: Yes.

R: so umm, I think we agreed beforehand that I would produce a transcript

P: Yes.

R: and that I'd like to show you that,

P: Yes OK.

R: Because these documents umm get seen others at the clinic umm. Umm and that uhh that we will produce a transcript, which, which we will look through independently and then I'll send you some of my thoughts on this.

P: Have great difficulty in eliminating yourself though Richard, I might, I might say *(laughter)*. No I mean umm uhh as far as uhh remarks made about doctors, I'm only joking.

R: No, no, no, no you *(laughter)* it's perfectly all right to say what you, what you want on the uhh transcript and I, I'll send you it, I'll send you mine

P: Yes.

R: and if perhaps you could uhh you could send it back to me

P: Yes.

R: and umm and.

P: OK thank you.

R: I think we'd better go for lunch.

P: Yes, OK that's fine.

R: It is 1.30.

P: Well is it as you expected? Let me ask you that question.

R: Ahh more so. I mean I, I, I umm **(2)** we uhh this interview arose out of kind of half a discussion we had a couple of weeks ago didn't it.

P: That's right and left me actually, not knowing just how you were going to structure it. Uhh **(1)** you would not be surprised that of course I have thought about it uhh and I have, I have obviously had to look across the wide spectrum of how you might present, wish this to be presented either a yes/no uhh uhh situation or whether in fact you would wish me to go into detail. So I have actually obviously thought about the detail uhh and that's been quite important because some of things I have actually push', pushed to the back of my mind. Uhh but I, they, they, they have umm been umm drawn back to, to the, the forefront as a result of umm me thinking about life.

R: What, what I mean I deliberately

P: I hope that doesn't falsify my because

R: No, No.

P: it's a natural process of umm preparing myself

R: Of course.

P: towards what would be a rather searching uhh interview, whatever form it might take.

R: Well, it, it, it, there was, it was deliberate initially not to have any, any kind of structure umm **(1)** uhh that I presented in that we, the idea was to negotiate

P: Yes.

R: the structure.

P: Yes, I understand also why you didn't want me to say too much at that time because we could never have gone through this again

R: No, it's a one off.

P: It's a one off isn't it.

R: Yes.

P: That's right, yes, that's right. That uhh that tape is still turning.

R: (*Laughter).* It is working. OK thanks a lot.

P: OK thank you.

APPENDIX 3

VALERIE

R: Thanks very much Val for coming.

V: That's all right.

R: You, you've asked me to have a little discussion at the beginning about what it is that I'm trying to do. That's why I'm going to start, start off by talking. I think we were going to also learn from this about what it is that you would like to get out of our chat because you, you have an interest in talking about this as well?

V: Mmm.

R: as well and, I, I will also address the question of confidentiality on video and if, if, if it turns out that things are unacceptable

V: Mmm.

R: you can always switch it off or

V: Yes.

R: either at the beginning, middle or end or at a later stage. I, as you know, work as a doctor. I work within a medical framework in which I obtain medical information and try and advise in the most appropriate sense. What I'm, have been interested in looking at .is what people do when doctors and patients with information that may be not medical in the strictest sense of the word, but maybe important in terms of determining what they do. And that involves trying to decide if, if that happens and if it happens what are the circumstances that bring this kind of evidence into the discussion. Do doctors permit patients to bring this in? Do they restrict access in all kinds of ways? Does the whole business of being, being in a conventional western framework of medicine make it very difficult for patients to make decisions. That involves looking very much at myself and how I handle this. What do I do with this information? Do I disregard it? Do I pay attention to it? Do I pay lip service to it? Do I, do I pretend to pay attention to it? But all the time underneath it, ignoring it but in a more subtle way. That sort of thing, but also asking patients how they construct images of their own illnesses and how they apply medical information in the conventional medical sense in terms of making the decision themselves. Is that clear? Is it?

V: Yes, that's fine.

R: Good. So, we are going to begin this well actually perhaps the best thing to do would be to

V: You're talking about it particularly within the realms of decision making?

R: I suppose so. That, that is the point at which a decision is made that, that forms the, the focus for, for thinking about these issues but of course these issues enter into a clinical context at all times without necessarily a decision being made. And yourself, what would you like to get out of this discussion?

V: I don't know. I am very interested in an area which I think the National Health is beginning to address and that is what the patient themselves is happy with in terms of treatment even though that may not always be the best in terms of whatever clinical measurement is available. That which might make the patient feel much happier and, in doing so, would allow them to relax and be more receptive to what ever treatment they do have and may end up perhaps producing a better result or perhaps in the patient having a better quality of life in their own terms.

R: mmm,

V: that's part of it.

R: OK.

V: And the other part of it I think is the, the awe in which the medical profession is still held by people generally, most of all by patients, prevents many people from feeling that they can address issues about their treatment with their doctors; indeed they rarely have the information to do so. The language of the medical profession is very technical and specialised, whereas the concerns of patients are usually voiced very much in terms of their feelings, intuition and fear of consequences. In addition fear of the unknown plays a large part in a patient's comfort and it is rare for this to be dealt with in a supportive way by staff without underestimating a patient's ability to understand what is going on.

Patient's fears or enquiries are likely to be addressed to the staff, who are readily accessible to them, the less qualified grades of nursing staff. Although these nurses are often most sympathetic to patients, they too have little or no access to doctors and in passing messages up the chain of responsibilities they can get distorted and delayed. These worries are often not passed on to doctors in a way that will produce the required information. The 'named nurses' system of allocating specific nurses to patients throughout a stay in hospital depends greatly on the ability of the nurse and can be frustrating for patients since to some degree it blocks access to someone who may be more sympathetic; but most of all in the several stays in three different hospitals I have experienced recently this system is very unpopular with nurses, who simply don't operate it.

Although much has been done to make hospitals more friendly places, including breaking down what seemed fearsome hierarchies of anonymous staff, according to all the patients I have spoken to, it doesn't help if they are left not knowing where they are. Not wearing uniforms and white coats and nurses being apparently more on one level and known by their Christian names, not having matron and so on does not help if they don't know where they are in relation to staff. They need to know who to speak to if they want a real difference and who is accountable for their daily welfare. They need to know that even more when they are really ill because they have no choice but to put themselves in the hands of a system which they feel will be watching out for them and have its own checks and balances. They need to know who can begin to make decision making, at least in part, accessible to them in a real sense.

It is most important for patient's wellbeing to feel that they have ownership and some control over their illness and that they can do things or behave in ways which will help themselves. The degree to which this is possible may relate to their recovery.

R: Right, there is

V: Is it a bit muddled?

R: No, no, not at all. I was thinking that there appeared to me to be quite an overlap.

V: Yes.

R: With what we're both interested in and, would that be fair?

V: Yes and I would like to feel that I could do something about things from a patient's point of view, particularly in the area of chronic disease as opposed to sudden or temporary medical cases. I think the treatment and quality of life of the chronically sick are much neglected because they're always there, they are never cured and the diseases sometimes progress very slowly. It is an unattractive area for medical research to address, an unrewarding one for Social Services because patients go on and on depleting resources and for hospitals because they continue to return to take up beds.

Most of all it is depressing for the patients themselves because the syndrome they are in is one they are mainly powerless to do anything about and they are cast in the position of having to take continually without being able to return. There is little relationship between their lives in hospital and those outside and medication and all the gadgets that tend to go with it these days become the continuing theme, their stability. This cannot be good but it would take major shifts in the system to change it.

Finally, I think that nursing the chronically sick is something that must affect the staff, particularly nursing staff. Those who do not have full and rewarding private /social lives which support them in their work must be affected by a situation in which patients rarely recover and get better.

R: Mmm.

V: Every way you look at it, chronic illness is a problem and a depressing one but it is so much more to the people who really suffer it because they, they are, in relative terms, used to being neglected. Sudden, life threatening or "fashionable" illnesses like cancer, heart attacks or aids are paid a lot of attention in the press and attract immense amounts or research money, while many chronic diseases cause more suffering to more people for longer lengths of time, cost the health services much more, but get little attention. It makes no sense. If I had had a choice at the beginning of my life as to whether I might go through life with the same progressive illness or be healthy until a sudden heart attack and die at a younger age, I may have chosen the latter.

(There is also another dimension flagged by the word 'fashionable', which is the social context in which diseases are perceived and therefore their sufferers. In the way that TB was perhaps the dominant fatal disease of the 19th and earlier 20th centuries, its victims were often portrayed in a heroic context in the culture of their time, as in La Traviata. Although one can easily imagine and indeed have read novels, etc. about protagonists with cancer or aids, it is difficult to imagine the same of chronic bronchitis, multiple sclerosis or one of the motor neuron diseases. This is not a thought out point, there is obviously a matter of degree with all of these things, but there is already writing on this subject and it definitely affects the way the medical profession, as well as friends and family, view patients.)

R: Right.

V: I've got a very nice GP who works with me patiently, explains everything and discusses issues of treatment with me. He gives me a fair amount of responsibility in managing my illness and when I need it he will take surgery time to talk. Usually I talk to him on the telephone and as a result I take very little of his time considering how ill I am and I call him out possibly once a year. However, there are things missing: there is no-one to tell me to stop, to take a rest and no-one to assist if me when I'm trying hard to keep going - particularly if I am trying to continue to work - and ones own inclination is often to push oneself way past sensible limits. The home-care services are no use to me, although I qualify for them, since they can only give help during working hours and you have to be at home at the time. There is also the extraordinary rule that they are not allowed to do any cleaning and for, say, asthmatics, this is perhaps the single most serious need. I have seen elderly sick people worn down and resigned to living in relative filth, when they have always been proud of their homes.

R Could I, I, I need to get your permission on video to transcribe this onto text,

V: Right.

R: And I, I would ask you to look at a copy and make comments, if that's all right with you and then I would also look at a copy and make comments and we can exchange it and have a look at the comments that we each make.

V: Mmm.

R: Obviously in the process of doing that, my secretary will, will hear what goes on. She's a medical secretary who will discrete. My supervisors, as well if it's OK with you because I think that I would like this to form part of my thesis.

V: Mmm.

R: My examiners as well; they will want to read the text and certainly would want to comment on it and after, after that , I am not sure whether or not it's going to be an accessible thesis, you can decide about that. But at any rate, all the identifying features like your name, are taken out.

V: Mmm.

R: Val, is that, is that acceptable? Can I just check that the camera is working before we carry on? .....I think it would be, I think it would be helpful for me because I don't know your full medical background. If you could outline what your medical problem is and I think the more difficult decision you've had to contemplate. Would that be helpful?

V: If you want me to talk about that, that's fine.

R: Thank you,

V: Would that, that help you?

R: Yes it would because I

V: Well I have bronchiectasis, which was first diagnosed when I was thirteen, which was the first time I was given any decent medical attention. It started as asthma when I was a baby and I evidently had chronic bronchitis by the time I was 5. I was put into hospital when my mother died, I was just thirteen, and they found that I had bronchiectasis and pneumonia and I was given antibiotics for the first time. (My mother died of stomach cancer having been treated for indigestion for years) We had been unlucky with our GP and this was changed when we moved house. About 1969, after leaving art school, I was declared disabled and I think there was no great expectation that I would work much. I spent long periods in the Brompton Hospital in those years. In fact after teaching part time in an art school, I threw the card away and got a very good job in the National Portrait Gallery. But I was 'economical with the truth' in my medical.

Lungs

To bring things up to date: my current diagnosis is bronchiectasis in both lungs and COAD (chronic obstruction of the airways disease). This combination means that I cannot have sustained oxygen therapy and I now have a Brompton PacK - a sophisticated positive pressure respirator - which I sleep on for about 8 - 10 hours a night. I have also been assessed for a double lung transplant. I would be above average risk for this operation and at present I have not made any decision to go ahead. (There is a lot to be said about how I am expected to make that decision.)

Twice, at about ages 14 and 26, I made decisions against my doctors' advice: the first completely instinctive and the second on the basis of my observations of other patients and my own quality of life. These and the decision I yet have to make about transplants I will deal with separately in order not to make this background too long.

Brain

Treatment for my lung condition is now complicated by the fact that about 2 years ago, it was discovered that I had a parasagital arachnoid cyst on the top of my brain, the pressure of which had slowly paralysing my right side for many years. I had been complaining about not being able to lift my legs up, difficulty walking and general loss of strength and exhaustion for some time, for several years at least, but it had all being progressing so slowly that it was, it was not diagnosed.

I think I'd been compensating for the symptoms for some time because I had been examined several times and did not exhibit any obvious neurological symptoms. People thought it might be lack of oxygen to the muscles etc. I thought it might be old age and so life had got extremely difficult, with the combination of problems, you know, for me to move around and I was constantly totally exhausted.

Although to have a diagnosis and to know that what I had been going through was not some kind of neurosis was partly a relief - I could relax and "give myself permission" to be tired - to have something wrong in my brain was terrifying. I remember during the early hospital treatment years in my teens, when after having my tonsils out they took out my adenoids and then started on the chronic sinus problems. Even having metal cannulas (?) pushed through into the sinus's from the back of the nose seemed so close to my eyes and what was behind that I found it very frightening. Also it is all out of one's own control.

So, cutting out the problems of lack of money for urgent operations locally and press headlines, I went into the National Hospital to have the cyst drained as that seemed to be the only way. I wasn't allowed to have a full anaesthetic because of my lungs and the position of the cyst on the motor and sensory nerves was such that the surgeon would only do the most minimal drainage procedure and would not risk a biopsy. He drained 15mls of the fluid inside the cyst, which held in total, I gather, about 60mls, on the day of the operation.

Three days later he decided to aspirate another 10mls. About three hours later that evening I had a massive epileptic fit. I was locked in the loo and suddenly enough electricity to kill a large oak tree just surged vertically through my body and I was completely rigid in a position that I could not normally even push myself into. It just went straight through mainly my right side and I felt all of it like a massive electric shock until I lost consciousness. Fortunately I'd screamed as soon as I felt slightly funny in that split second it all had happened and the last thing I heard was someone saying the door was locked. They got me out and a nurse afterwards told me that I was blue all over and not breathing. They couldn't get oxygen into me with the squeeze bag because my teeth were clamped - but whatever they did they got me back conscious within about 20 minutes, telling me they may have to do an emergency brain operation.

The next day the surgeon told me that it was a provoked fit and I would be unlikely to have another, they would put me on epilepsy pills for a while. They did not listen to me about the extreme pain - they were assuming that I meant some kind of pins and needles and later I gathered my experience was rare.

They sent me home after a further 3 days. I rested with some friends for about a fortnight, and was being brought back to stay at home with my sister and on the way back between Bristol and Bath I had another seizure in the car. Umm and I couldn't speak and it was affecting my throat as well as all my right side and umm I managed to sort of say 'hosp' and get taken to hospital by my friend and umm there - Do you want all this?

R: Yes, that's very helpful.

V: The duty House Officer, although I told him I was under Dr X, sent me home because he said there was no surgical neurology person there and to ring my doctor. I got home and my doctor was on holiday and the locum wasn't there and I rang the National Hospital because it was a Friday afternoon and I thought, I know what's going to happen here, they're all going off for the weekend as it was Friday. So umm anyway, I spoke to umm Dr Y at the National and he said "I want you to have a scan straight away and come here" and I thought the last place I want to be is on the motorway. He said is there one down there. I didn't know. Anyway the doctor finally spoke to Dr X, my doctor, my locum fortunately; umm all this was late morning, early afternoon and by 5.0'clock Dr X said he wanted me back in the RUH urgently. It emerged that he didn't know that I had had the operation. His SHO met me and the he actually came down to see me himself and I was speaking to him for about 5 minutes and I went into another major fit. I had, sorry, I had had two more fits during the afternoon getting stronger and umm I was in this last fit strongly conscious but unable to speak. I was on Phenytoin and Diazepan, for five and a half hours, four of which they could not get any Carbamazepine since pharmacy was closed. I finally got into the ward just before midnight. Umm but all of that was excruciatingly painful and I, I've learned since that it is very unusual to feel serious pain or to stay conscious and I presume, they presume it is because the cyst is on the sensory and motor part of the brain.

R: Why, why there was so much pain.

V: Yes. But I literally felt all the electric shocks which were going through my body. Anyway that complicated the issue of whether to have transplant surgery. I haven't had any fits since the second lot because I'm on quite a good dose of 2 epileptic drugs and it took quite a while to get stabilised. It took a while for me to feel, you know, safely confident to go in for the transplant assessment and then I was immediately told I probably couldn't have one because of the epilepsy, although they'd known that before they got me in there. They stopped all the tests that were booked because they did not want to waste the money, but in the end they did not get a positive 'no' from a couple of surgeons so they went through with all the usual assessments except for the final invasive one, and they were all fine. I mean this is when I'd psyched, I don't want a transplant and I'd psyched myself up for weeks about it and I'd got into hospital and that afternoon the, the day I arrived, I suddenly told myself, yes I thought you wouldn't get one. So it's, it's been very up and down and it was only the year before that I had the that I'd acquired epilepsy which of course after the second lot of fits is a permanent state and I shall be on the drugs for ever. So it is a second sort of chronic umm problem and it will, without doubt, complicate the transplant possibilities because the epilepsy drugs and the anti rejection drugs don't suit each other. They have had one or two patients go into permanent epileptic fits and die literally during transplant either under the anaesthetic or afterwards. So I am there at the moment and I am still working nearly full-time.

R: Yes. Very impressive.

V: And umm I, I've been through and I've got used to my prognosis if I don't have the transplant so I don't know how much more I can stand.

R: Do you want to clarify that?

V: Basically I have to clarify the consequence of having the transplants as well as not having them.

R: mmmm

V: Is that what you want me to say?

R: But you ask me, you asked me if it's what I want you to say.

V: I don't want to be entirely indulgent but I'm certain I want you to get what you need out of it.

R: Well thank you, but, but I feel the same as, as well.

V: Well shall I quickly sum up the two things about having it or not? There is evidently what they call a 70% success rate with lung transplants roughly at the moment. To clarify that what they mean by 'success' is actually survival within the first year and the 70% goes down to 60% if you've got bronchiectasis because I gather, I learnt this when I went to Harefield, it's more dangerous to cut the lungs out when they have adhered to the chest wall and there is a lot of bleeding which they find difficult to control etc and as they say I'm over 50, and I say I'm a very young 50 and I'm only 52 but this umm this age thing also becomes a huge problem which I really feel has major implications. In addition, with the problems with the epilepsy drugs, it probably doesn't give me much more than a 50% chance. By the time I'm 60 I won't be able to have a transplant at all anyway.

R: I didn't know that.

V: I'm down to 60% possible likelihood of survival in the first year already and then there's the problem of balancing the epilepsy drugs and having more fits and all the rest which, you know, I reckon in real terms possibly takes me nearer to 50% likelihood of survival in the first year. And then I asked the surgeon 'out of the 70% who usually survive the first year, how many of those are still in hospital?' and he sort of stuttered a bit and said well he was sure these figures are available somewhere (laughter) and I said 'well you guess, you're, you're a transplant surgeon, how much do you think?' And he said 'well about a third.' And that is a huge proportion of 70% down because in order to be in hospital these days you have to be pretty ill.

R: Yes.

V: And I know they send transplant patients out as soon as they can, so the consequences of the, that proportion off my 50% does not seem very attractive. The main reason I don't want one isn't the fear of the operation at all, it's the side effects of the drugs. I've been on long-term steroids before and came off them about three times because they have such bad side effects with me. As well as being on steroids, there is cyclosporin, which is the main anti-rejection drug and has some similar side effects as steroids but it also has others: cancer, fatal infection due to lack of immune response, osteoporosis and kidney failure, yeah they are big things. That's leaving out all the little ones. I mean what is one letting oneself in for? He then said after that chronic rejection syndrome sets in. At the moment it's a little over 2 years and but that on average patients live with it up to about 5 years and then between and 5 and 7 years during that time there's a steeper drop and that's the sort of average time for fatalities. Well what are we talking about? The suffering that would be involved in going through those side effects and really feeling rotten on the anti-rejection drugs.

The longest surviving patient I've spoken to, and she is in her 11th year, nearly 12th year, and she is, she is bright and she talks you up as she obviously would, but she's got osteoporosis badly, she's got kidney failure and I don't know how long she's had them. To me I feel as though I can survive. I've got used to it. I, I did feel after seeing him that I

would come out, get myself into some clean air, possibly stop working, although I don't know about that as it has huge social and personality implications with me because I live alone and I, I, I felt that I'd could do at least as good as the 10 years and I wouldn't have all the side effects of the drugs or the constant control or hospitalisation in Harefield. So I went back to see Professor Z at the Brompton and I said, 'what, you know, what's the situation?' He said, 'well you're not going to be in a very good state after about 9 or 10 years from now if we take the progression that your disease has made over the last I think 7 years, which are well recorded. If you progress at the same rate, you won't be in any fit state really in 9 or 10 years time' and I said, 'well what do you mean by that?' And he said, 'well you won't be here'. So I said, 'OK' and, and he said 'it could be considerably less than that if you get bad infections and frequent infections.' So anyway I asked him, 'is it mainly infections that governs the deterioration rate? And he said 'yes'. And I said, 'well I want to know how I would die because I sort of want to plan, I want to know what other people are going to have to put up with from me and I want to be prepared to be, you know, able to control as much of it myself as I can and be in little of the pain that I need to be.' He basically said, 'I wouldn't.' I said 'I was hoping my, my lungs would put such a strain on my heart in turn I would have a heart attack' but no such luck. He said 'it would gradually be more and more of a strain on my heart and I'd get more fluid around my heart and lungs and gradually the heart would be less able to pump the blood around the body and the organs, the other organs wouldn't get what they needed and they would all gradually begin to fail and then I would get, you know, less and less with it and a bit sleepy' and so I understand that. It's a long process again and it goes back really to the point about the long chronic illness argument. Umm I still think maybe I can do better than what he says but I, I don't know. I know I've already got through so far so that's it.

R: Thank's Val. There are lots of questions I want to ask you but the one of the things that I noticed, was when you described it all that you use a lot of very conventional medical terms and a lot of the medical language. I mean it's a very sophisticated description and I would think from a medical point of view, you're extremely well informed. Is that how you view it all? Is that how you construct it in your mind?

V: It's the way the doctors tell me.

R: Does that, does that fit in how you'd like to see it or have you just found?...

V: Yes in a sense that I want to understand the doctor's language so that there is less of a divide between us. I think it's also completely umm unconscious result of having spent a long time and a lot of my life in the company for short minutes with doctors and listening within hospitals and things and not everybody would necessarily listen and pick up things like that but I do. I don't think one can underestimate the umm knowledge that anybody with a chronic illness gets of their illness and they certainly have a very, very strong idea of what is going to be good for me and what isn't and it, it quite often is right. It usually, it's, well it's always based on experience obviously because I wouldn't, but it's all usually based on experience also of at least one doctor that I'm in contact with either at the hospital, or my GP who is fairly experienced at the same time. And I sometimes get

sent to different doctors or am in a strange hospital if I'm somewhere else and umm and they have a completely different way of dealing with me which actually is, is very distressing

R: Mmm

V: And it's very distressing if a doctor won't listen to you at all about what you know is good for you for instance and there are doctors in all, all hospitals and all surgeries like this and they are usually slaves of either the latest medical text book or the one where they trained. Most doctors keep up to date and they've got a hell of a lot to keep up to date with but I just, I mean there are contradictions now between the Brompton.....I had a short time in hospital in the RUH last year

R: Yes.

V: having treatment and I got, am, am now on a respirator, I have been for the last year, which has made enormous difference to me and I don't think I would be at work without it. It is the Brompton Pack and it's a positive pressure respirator but it is a special one that's built to respond - it responds to my own breathing. It suits bronchiectasis patients because it, when I breath, different bits of my lungs will stick together and I don't have a regular breathing pattern, although set to basic pressure, inspiration and expiration times, will alter with my breathing. Anyway, the doctor down here was absolutely convinced that a positive pressure machine like this would push all the infected sputum down to the corners of the lung where it would then fester, you know, and

R: Create problems?

V: create the usual problems. Well in fact it doesn't. I've never had such clean lungs and it's cleared them out. It clears out at the ends of the, you know, the ends of the alveoli, the sacs that are there, but I don't know what's still down there but it clears it out a lot. And also before this, Frusemide has had an enormous effect on my lungs and, and that's the second story. About six years ago in the winter I had what appeared to be heart failure which my GP put me on Frusemide for, with immediate relief of all symptoms. After two or three months he took me off Frusemide and as soon as I was off, I felt awful again and my lungs were very wet and, and my breathing was worse and I said, 'you know, can I go back on it?' and he said 'yes OK.' But he sent me also to be checked out by the heart consultant at Bristol Royal Infirmary. They couldn't find anything wrong with my heart, there was no evidence of heart failure afterwards but I had all the classic symptoms when I was initially put on Frusemide. I went up to the Brompton for my next appointment and this doctor just wouldn't listen to me saying that I had been much better and had had fewer infections since being on Frusemide. He wanted me to go on steroids again and I had really bad side effects from steroids and quite frankly, if I'm on steroids for very long I'd go and throw myself off a bridge. I've been on three times before with the doctors at Brompton. They've all agreed for me to come off and he wants to try it again in larger doses. Umm and I say, 'well I'm actually a lot better on Frusemide. I want to

stay on Frusemide through the winter and just see how much my infections are reduced because they certainly seem to be reduced over the summer.' And he said 'well you can stay on this if you like, but you're going on steroids as well.' So umm I said, I said to the consultant, 'if you put me on steroids and I stay on Frusemide and I have a better winter, you're going to say it's because of the steroids and I'm going to say it's because of the Frusemide and you won't know which, which is which, what's had the effect.' Anyway he wasn't going to change his mind so I went back home fairly stressed by this interview. I went to my GP and said 'I wasn't happy with it,' and he concurred and let me stay on Frusemide without the steroids and I did have a much better winter. Went back, asked to see Professor Z, my usual consultant the following spring and said, 'look, I've been better. I've had a better winter, I've only been on Frusemide', and this had been going on by the way over a period of a couple of years by then, which I had been saying I was better on Frusemide. I told him everybody said that it was not doing me any harm, so I could stay on it, but there was no reason at all why it should be doing me any good. Anyway, I saw Professor Z and I told him this story and said that I had been significantly better and had fewer infections and I said 'the other doctor wanted me on steroids' and he knew, he's known for a year, I didn't want to be on steroids. Anyway, half way through this story he started to grin and he said, 'I think there's someone down the corridor who'd like to meet you' and he took me down to one of the Registrars who was doing research into the salts in the lining of the lungs

R: Mmm mm.

V: because the balance of salts in the lungs affects the efficacy of the, the, working and moving phlegm from the lungs in a continuous way. And, I mean, one of the things I found that the Frusemide also did, it's much easier to cough up sputum. I could clear my lungs much more easily and there was much less of it. I went to see him and he was most interesting straight away and said, 'yes you're right, you know, it affects the lining of the lungs' and of course Professor Z being bright, realised immediately that Frusemide would affect the salt balance in the body, not just in the kidneys or wherever, you know. He made the connection but only after 3 years, you know, the relative arguing, they suddenly decided I was right. Umm and that was from what I felt and, I mean, what I'd observed. But I have to say that the, the registrar doing, who was doing the research is still at the Brompton, did say that it was unusual for patients to observe themselves umm in an objective way accurately. I don't know whether that's right or not. He said most trials, most studies with patients had not reflected what their accurate clinical state was and that's when my other interest comes in, in a sense that maybe doesn't matter if they feel better.

R: Umm yes. Sorry, I'm dying to ask you lots of questions.

V: Go on shut up, shut up!!

R: No, no Val. You mustn't do that, you mustn't think that because what you're saying triggers off lots of questions to me obviously. Ok, I'm interested in that moment

when you, you find that what you feel is instinctively the right thing for you to do. When it comes up against the conventional medical explanation, although you seem to me to, to go into the conventional medical explanation and handle yourself pretty well by putting forward logical medical arguments for what you're doing. Is that actually what you're thinking?

V: No I don't at the time

R: Right, how do you think of it?

V: The Frusemide thing, what I've just said? Afterwards I was told that, you know, at the time when they all decided, well a few people decided, I was.....

R: When you had to decide whether or not to have Frusemide and steroids over the winter, you said, 'well if I'm better at the end of it'

V: I know, that's umm, that's fairly logical. Anyone could see that if you're doing two things at once

R: Right.

V: both of which were supposed to make you better, you wouldn't know which it was would you? I mean this, this happens with a lot of drugs now umm and uhh I think people are much better at watching themselves

R: Than they used to be?

V: Mmm.

R: Where, where, where is the source of your certainty about what's good for you? Where does that come from? You said experience?

V: Well it comes down to gut in the end. It's gut reaction based on experience and umm weighing up the odds umm and the choice to have at the time. Further – it is gut reaction based on a lot of experiences, of feeling really ill from medication.

R: Ok that's interesting. When you take, take that, how do you, how do you get it into the equation?

V: That's an interesting one because that's what I've got to do about the transplant in the end. I have a friend whose daughter, who's one of my very, very good friends and who's been great support to me for some years her daughter is a councillor with London Underground. So when I went up to London to be assessed for the transplant, I actually, I asked her if she'd come and see me and I said 'how do you decide between two things that seem as bad as each other? Because I mean the time that Professor Z was giving me,

not that I realised this then, and the kind of death he's described, is not that significantly better than the transplant except that of course it's much less invasive. But basically I asked her 'how do you decide between the two things, neither of which is very attractive?' And umm she came down in the end to something that .....

R: She said?

V: to obtain all the information you can about both, you know, both treatments.

R: Yes.

V: and the consequences of, consequences of the treatment and think them over for a time and my gut reaction would come up. That always happens with me. Somehow, you, you begin to know exactly what you want to do and you then start thinking of the reasons why. I mean there's a, I mean it's very instinctive thing or intuitive thing I mean I'm quite intuitive about most decisions I make about things anyway. Anyone who thinks like that makes decisions fairly quickly usually and then has to substantiate the reasons why.

R: But you...so once you, once you collect the information, you allow an intuitive decision to develop? Once you've developed that intuitive gut feeling decision, you then construct an explanation based on the evidence you have collected?

V: That's not quite right, you, no, I'm not closed at that point. It usually turns out to be the right decision. You then say, 'well Ok, well why, why have I made that decision? Why does that seem to be the one I want?' and you look at it again and that time the logic falls into place but also at that point I will still at any time listen to further arguments from doctors because my construction might not be right. Or something may have happened to change things. But you see, there was, there are two other things that have happened in my life in terms of big decisions. One was when I was fourteen and I remember little about it, I didn't know why, I did it; I did not consciously formulate any reasons why at the time – I just heard myself saying 'No'. But I, I, I'd had a GP all my childhood who did nothing but give me Franol tablets and tell me not to go swimming and keep warm and he gave my mother indigestion tablets all the time for a bad stomach.

We moved when I was 10 years old and my mother was investigated very quickly and it turned out she'd got fatal stomach cancer which had gone on for too far too long to do anything about. And when she died I was put in hospital and by then I'd got bronchiectasis as I said, but from then on I did get regular hospital treatment and when I was 14, I was, I was still taking Franol, which was a white tablet. And one day on a visit to the clinic I was given another white tablet to take, a small one, and was told that I'd got to take it regularly. It was most important I should take it at the same time each day and nothing more than that, they told me nothing about it and there was no reason or precedent that would make me refuse it. And I was, you know, frozen. I would not take that tablet and I didn't know why. I went back home and my father had not been unable make me. My aunt also visited but I didn't take that tablet. I don't know why. I went back to the clinic,

he questioned me very kindly, over some period of time. I don't know why I wouldn't take that tablet but I wouldn't. It was Prednisolone, which I realised much later that had I gone on it permanently then, I would have been dead long ago.

You know, I've got very strong feelings about the use of steroids and in hospitals and elsewhere. In fact it became necessary much later in fact at the Brompton for me to agree to go on steroids when I knew slightly more about them because I was very bad and so I said, 'Ok I'll go on them.' By that time I knew a little bit about them and I'd seen people on them in the wards and I was on them for about 15 months. They kept saying yes, yes continue. I was still getting asthma, and it was no better. I put on a lot of fluid weight, my hair was growing very thickly, my eyebrows were joining up with my hairline. I'd got swollen knees and ankles and indigestion problems and I just couldn't see how anybody could think that this was good for me and the answer to my lungs. Finally a young houseman that I saw in out-patients listened to me and thought and said, 'well I think you're right' and had the guts to go to the consultant and say so and I got off it. But basically that happened twice. I went on ACTH and gave myself injections through trips to Paris, etc. and you know, and I, I took the ACTH and went and got off it and that happened twice because they were so convinced that it was going to help me. It never did help me and the third time came when I was very ill again. I couldn't walk down the road at all. They insisted that it hadn't helped me before because I hadn't had enough of it and I'd got to have higher doses and I said 'No'. That was the only time I had actually said 'No' to treatment in advance, other than the time when I was fourteen.

So the Brompton then said, 'all right, you can get a second opinion' and I was sent to UCH for a second opinion. They said exactly the same: that I needed higher doses and I went back and I still said 'no'. This felt scary, because to cut oneself off from the one place that had always helped me, when I couldn't breath was no light thing to do. I felt misunderstood and didn't know what would happen. By pure luck, somebody that I was in contact with put me in touch with a Consultant in the Edgeware group of hospitals. He was the consultant chest physician, Dr A-B, who is dead now unfortunately. He was using ordinary antibiotics and other chest drugs, bronchodilators and things in conjunction with auto-hypnosis; but only on patients who were not on steroids. For some reason it didn't work if you were on steroids. He accepted me and all that and I, I was in hospital for about 10 months. I had lots of chest infections and I had lots of antibiotics and drugs and went through quite a time and learnt to do auto-hypnosis straight away and I did it all through the time in there and saw several other patients in the same situation and from that time on, I, I didn't have a pure asthma attack ever again. I mean, I still do it, not often enough, but from that time on I've only had asthma and exacerbated wheezing in conjunction with infections. Before that, in my childhood and later, I was having horrific asthma attacks, you know, umm triggered not by infection, who knows what and umm I was wheezy all the time. Whereas from then on, I was only really wheezy with the infections and obviously the bronchiectasis was slowly progressing but it wasn't this overlay of panic wheeze and other things. I think he was quite remarkable and he appears to have been totally lost from the record books which I think is a great loss, you know. It is a completely harmless, calming technique.

I have also since that time tried various alternative things like the Alexander technique or various alternative medicines at various times to just keep myself in as much as an erect, mobile, flexible state as I can, because that's also what's important. When people are just sitting all the time, especially with chest disease, you become very immobile and rigid and pained, with an infection, I mean. I find I just get up and move, twist my body, you don't have to do very much. You can put on a slow record and be slightly moving, as long as you move your arms and chest around, then the phlegm for instance will come up, it'll all get moving and I've seen patients sitting in hospitals, not eating any of their meals eating cake, eating God knows what. The doctors come round on their rounds, the patient's very bad. The Sister's saying oh they're not eating their meals, you know, and they're sitting with oxygen masks and it's, it's a sad state, when I was in there - Which is the one in Hampstead, the bottom of Hampstead?

R: Royal Free?

V: Royal Free. I was on the 7th floor there and there was a particularly bad case of a lady stuffing cakes between her oxygen mask like this, not eating any of her food and I couldn't stand it. I just used to walk out and walk down seven flights of stairs and get the lift up again several times, morning and afternoon, because walking down takes very little breath, although I can't do it anymore without getting out of breath. I mean, until you're really bad you, you can go down them very easily and the important thing is to keep your body, your whole body, in a state that can deal with things so that, I mean, I paid for all the alternative stuff. I paid with energy and exhaustion to keep going to work and things but I think unless your, your mind and social life, and I'd rather go out to supper with friends and cheer myself up and collapse when I get back and perhaps have a bad day the next day and recover than stay in for two more nights and get depressed. Getting a taxi doesn't hurt you. I don't know, I've just said a lot of silly things.

R: No, no not at all. Why do you say that?

V: Well we were talking about decision making and why I was so convinced. I haven't managed to keep a train of thought have I, lack of oxygen is very good at killing off your train of thought. Take me back where you want me to be. I haven't asked you at all. Why don't I ask you some questions?

R: Well you can if you want.

V: No it's all right, you can carry on.

R: I, I'm interested in the way you react to the medical profession as a whole.

V: Well for instance, that last thing, I mean I think they're past it these days but I mean, you know, the nurses and the doctors not to have known what a woman like that is doing and saying no cake or something is ridiculous.

R: I, I didn't mean it like that.

V: Sorry.

R: I meant in a sense that you, you submit yourself to an organisation and the doctors and hospitals and everything that goes with it - do you do that willingly?

V: That's a good question. Not usually, I.... it used to be quite willingly

R: Sounds as though there's an element of wariness about that.

V: Hospitals are not such benevolent places as they used to be - such helpful or nursing places as they used to be and I think it is probably a quite conscious policy which hasn't been thought right through. I think that a lot of what is wrong with the nursing profession in terms of patients experience and nursing experience is that they are no longer taught to nurse. And I found it quite ironic that this is the case in a period of time when doctors on the whole are becoming much more aware of the value of various, you know, therapies at any rate you know making patients feel better generally about themselves. Nurses, like doctors, vary tremendously as people and the changing, more technical, university training is intended to attract a wider group. Also, with the shortage of jobs and the break up of tight family groups, many people will be attracted to nursing who may not have any experience of caring for people. I believe it is something which can be taught, but it is no good teaching without understanding why - its therapeutic value; it is something which should make up a large part of the ethos of nursing courses. You know, the last ward I was on, the sister never smiled once, none of the nurses smiled, they didn't say good morning in the morning. It's very rare now for the nurses just to go round, sit on the bed and chat and see how you are and it is not because they never have the time – they do - but they talk to each other, often over the heads of patients. The system of actual having a nurse you know....

R: Attached to you?

V: to patients doesn't work at all. Most nurses don't want to do it and usually they'll get out of it if they can. I mean, in my experience, it might not be wrong as an idea, but it's not something that's working very well and I think that for the to nurses feel a joint responsibility for patients is much better. I mean the nurses often take better care that way anyway. If you have a named nurse who couldn't care less, or is off duty for four days the day after you are admitted it is hard luck. I mean if you've got nurses, who are bright and cheerful and talk to you and see how you are, I'm talking about very ill patients as well, and you know tuck you up or help you eat; I mean some patients do need help. A lot of patients are elderly and I've seen a hell of a lot of that. The nurses also resented how other patients felt. There was one patient I remember. That's one thing that I, I'm most frustrated about being in hospital, is that I see elderly patients not eating, maybe can't reach their food or don't want too, they're too depressed. Nurses really don't like it if

another patient gives some help whereas I, I forged several really good friendships with older women on the wards I've been on through doing that and I've been aware that I'm not necessarily popular for doing so. It is extraordinary, the close, albeit temporary friendships that are made between patients in hospital to the extent that their closest anxieties and experiences will often be shared within a couple of days of being in the next bed. They will be informal and clear about their worries when dealing with authority they may never ask the right questions of the nurses or doctors.

R: mmm

V: Yes, and I, I kept... I mean there are a couple of partially sighted patients and pure accident that I'm running Green Park Station and the Society for the Blind and Partially Sighted is one of my tenants. It's been pure accident that I've overheard their name since and they've not been happy about going to Day Centres and that sort of thing and I've gone out with a Blind Administrator for the day and in one case persuaded a lady that I got to know quite well in hospital, by being quite cheeky, to go to the day centre which gave her husband a break. That was a connection between hospital and outside umm in a friendly way which I just wonder whether something like that can't be worked somehow into the system even in a voluntary way

R: That may be possible. Well, why do you say hospitals have become less friendly places, less supportive?

V: I think it's because the nursing training has changed so much.

R: Why do you think that?

V: I don't think it's, I don't think doctors have changed that much, umm, I think, no, doctors have changed a bit and it's for the better but the, the whole atmosphere of the ward depends on the nurses part and.....I, I've told you before about my story in the National Hospital where I was on the surgical ward and talked to patients in a friendly way but as for the nurses, the whole time I was in there, they didn't to me. I mean fortunately I talked to my doctor. I mean the only friendly thing I remember from that experience was holding the hand of a wonderfully warm South American woman doctor who was a patient in there and she had a great smile and she was South American and Latin and warm. She was that kind of person. It wasn't because she was a doctor.

R: Right.

V: and a patient, and the horrendous experience I had of this woman that came in the bed opposite me. Who was almost completely disabled in every respect except that she could hear and speak but she was blind She was only visited once by another disabled person who had come a long way. She was totally ignored and I discovered after two days that she didn't know why she was in there. I was appalled and I asked whether she wanted to know and she said 'yes she thought she ought to know.' She was dressed daily

in these very dark glasses but she had nice eyes, which I told her, she'd had no idea. On the ward nobody had talked to her except one male doctor who was really good and he was on what-you-call-it? He was just in the National for a month's training.

R: On attachment.

V: And going back to something Park.

R: Northwick Park?

V: Northwick Park. He was a wonderful nurse and they're so rare nowadays. He used to, used to bath her and get her out of bed some mornings but when he did it, he talked with her the whole time, he chatted a lot. He moved her around in a, you know, in a really caring way. Umm the others, you know, got her undressed, got her strapped up and stuck her in front of the television that close and I said 'that well she really couldn't see' and all those nurses all day, all were behind the desk observing the acute patients just back from the operating you know ward, operating theatre section of the ward. They were behind the desk and they were chatting among themselves and the doctors. They never chatted to anyone else. That's the extreme end of it. But I think it's less satisfying for the nurses as well when you don't have a warmer and caring atmosphere. Mostly umm the nurses that train nowadays have less experience of nursing in real life, in their outside lives. It ends up with them not getting real satisfaction in their jobs.

R: Mmm.

V: I think people in many cases need to be taught to care and they need to be told, shown how to care. I mean they're not used to dealing with, you know, bed pans and things like that. I mean I could get down to very basic things. When I was fourteen and first in hospital, I got out of my bed and went across and held an old lady up behind the curtain because she's in a position that she can't go to the loo, you know, and she's been left there for hours, lying down flat over one of the old metal bedpans. The most tiny things that I mean, to me, most of them are instinctive. A lot of people, they're not instinctive to it and it's not their fault and I think people need to be, nurses need to be taught how to care for people and the other thing, the whole thing of actually making the ward a cheerful, you know, engaging place is, is you know....

R: So do you, do you see a relationship, or am I just putting words into your mouth, between the more technical side to medicine and the ability to care? The more technical it is, the less there is a medical need to care?

V: I don't think it's necessarily the case but it's umm it is the case that nurses now are taught very much I presume the technical side of caring for people and umm you know, very much less important, if any, is put to the personal caring for people and they have so much to do as well.

R: Yes.

V: That it doesn't allow them much time for that maybe but yes, I mean it is but I also think that some people, they've got it automatically and some people haven't.

R: Right.

V: But in the, the training's not picking up perhaps the larger number that haven't.

R: Whereas it used to in the past.

V: It, it, it used to in the past because a lot of, I mean.... when I first went into hospital, my bed was made 5 times a day. Matron came round to see if you're Ok. There are no matrons and although everybody went weak to their stomachs with some matrons you know, Matron actually checking up was not a bad thing. And although you don't want your bed made 5 times a day, you do want it comfortable if you're ill. You don't want rough sheets under you. You don't want things sticking into you. You know, when somebody's bed is made and they're really ill, it's a caring thing. I know it sounds daft to most people probably, but they sit out and they chat while they're doing it and they're put back in and their pillows are made right and those few minutes

R: It's a social time.

V: It's a social time and they're made comfortable and they're cared about and if that happens a few times a day, it's good thing.

R: Does that make it more difficult for you to present yourself as an individual with individual wants and wishes?

V: No of course not. It gives you time to actually do this.

R: If the system doesn't do that, does it become more difficult?

V: Yes, oh yes because if the system doesn't give you the opportunity it will also be underlining that it is not required to in the nurses and doctor's minds, and they will not make any attempt.

R: Is it that the system depersonalises you? Do contradict me if you want. Is it part of the system, part of making you a medical problem? Would that be so or not?

V: Yes, it does objectify patients in that way. Patients are not part of the whole social unit of (orderlies), nurses, doctors and managers and I think this increases the medical problems as well, by taking away responsibilities from the patients. It not only disempowers them in social sense, but separates from their illness in a way which creates anxiety and makes the illness itself the only way they can get attention. This surely can't be

a good model, but it is one which is continued outside the hospital, which can make some patients want to come back.

R: Right.

V: I think that if people are less happy and not cared about, they're not going to get better happily and they are not going to feel, they're not going to feel in a physical state where they feel like getting better. I mean, I know that there's always been this argument, it's a bit like prisons, if you're too comfortable in there, you can't get rid of people.

R: Yes.

V: They'll want to keep coming back. Ok that's a real problem but I don't see why that problem can't be addressed umm head on. Why should you make people uncomfortable in hospital and dying to get home in order, you know, to have them back a few days later with something more seriously wrong with them?

R: Ok, I'm sorry to interrupt because I do, I, I really want to push some things that I'd love to check out with you. One is this...it's, it's occurred to me from what you've said that if hospitals become less overtly caring and it becomes more difficult for you to present to the system non medical bits of information

V: Mmm.

R: it's a way of simplifying a problem so that you then become somebody with a lung problem without everything else bolted onto it and simplifying the problem is one way of dealing with the problem.

V: Mmm.

R: Now do you think that's a fair construction?

V: Yes-that is what I meant about abjectifying the patient and making the illness that only point of interaction. (Freudian typo left there – I thought it was quite good!-Val)

but it misses a whole lot of things because

R: Right.

V: a person with a lung problem, a happy person with a lung problem

R: Sorry I'm not saying that, that's a good thing.

V: No I know you're not. I'm trying to, it's a bit difficult with this. The point is somebody who is happy gets a bad case of whatever it is and goes into hospital.

R: Yes.

V: is treated well and comes out. It'll be an experience which will you know, gradually fade in their memory and they will deal with it in a healthy manner. Somebody that has a problem and goes into hospital and really when they're in there they are not made to feel welcome, they are not nursed, although they are feeling really ghastly and they aren't able to tell the doctors and nurses all the things that are worrying them

R: Yes.

V: around it, will not get the information and everything else that they need to know about the illness. Patients have worries and even though they might be silly ones, that a nurse could answer in half a second while they're making the bed.

R: Yes.

V: They've got to get rid of those worries and they've got to really feel more positive in themselves generally and if they don't they won't get better so well, so I mean I think it's actually useful. If we are making everything more umm technical and ignoring the other side of people, people's worries about their illnesses, it's, it's I think making more problems in the end and if I think it's affecting, I think it affects the nursing staff and it makes them much less happy in their work. (These 'worries' all the time are standing in for more complicated issues.)

R: Right.

V: You can see it.

R: Yes.

V: And you know, all they're worrying about is whether they've done the last bit and when I was on the chest ward, what's most important to me is to get about eight hours on my respirator at night. Sometimes it was half past twelve before I got my last injection, you know, intravenous injection because they have so many to do on the chest ward and you know, you're woken up at six for the next one. I'm only in hospital when I'm at my worst, when I most need the respirator but even here the technical (medication) is working against the caring (making sure I get enough oxygenated rest.). It's, there are, I don't know, I mean they may be very short of staff and all the rest and I don't know, that's neither here nor there. I said this to Dr X. He had a really, really lovely Indian SHO who you probably know, who used to come into the ward very softly. I noticed by the way that all the staff always called him by his christian name not his surname which they didn't do with most doctors but he would sit on you know, sit on the bed, he would smile at you. If he came into the ward and caught your eye, he'd smile and say 'hello, good morning' or something. All the other doctors, especially the young ones, they're terrified. They've got

steel on the heels of their shoes or at least they've mostly got hard shoes. They come across a ward, clack, clack, clack, all the way over. They ignore everybody's eyes. They never meet an eye and they go to the bench and thing, whatever and write it down and then they go and see their patient and it's a kind of total funnel tunnel. It's impersonal and all the rest and you can't, I mean, it, it's been like that for donkeys years and I'm sure it's it's partly in the beginning for doctors a kind of mixture of fear and apprehension and all quite human things as well but it's also to do with esteem and arrogance and the different position in the hierarchy between the nurses and doctors. I don't think it should be perpetuated you know when they come in. I think it should be dealt with and I think all doctors should wear shoes that do not make a terrific noise when they walk across the wards, especially at night.

R: What, what does that tell you about the hierarchy for the position of patients in the ward then?

V: Oh well patients are there to be seen when the doctor's ready and only then.

R: You said 'doctors' Are doctors on top and then nurses? Where do the patients fit into all of this? Underneath, in the middle, on top?

V: Well I mean, none of them would be there if it weren't for patients but I don't think they remember that

R: Laughter.

V: I don't know where they fit. They're there. I suppose they are. I mean they have to be underneath, but it's not a, it's not the same logical thing, as nurses and doctors are all employed for patients.

R: I interrupted your train of thought on this. You were talking about doctors going through the ward making noise. That's what prompted me to ask a question. What is walking through a ward noisily at night saying about the environment.

V: I don't think, I don't think they think that consciously. I don't think uhh, I think there probably is a lot of apprehension in young doctors first going onto the wards. It must be pretty scary and I also know that quite a lot of you know, the way I mean, if you, you are experiencing seeing terrific pain and suffering or whatever, they would need to protect themselves and build up their own way of coping with it.

R: Yes

V: and I'm not talking about myself at the moment, and they see it repeatedly all the time and they have to develop a way of dealing with it. They have, I mean, you can't react to that as maybe I would or a patient would every time so they develop different ways of dealing with it I think

R: Mmm.

V: according to their own personalities. For some it is easier for patients to meet than others.

R: But I am suggesting that the organisation may allow a doctor to behave in certain kinds of way because, although you say it's a thinking process for a doctor to walk across the wards noisily at night, the organisation somehow permits that as an acceptable act. Yes, there may be reasons for that as you say.

V: Well they're allowed to wear whatever shoes they like. I suppose lace ups or whatever.

R: Well I, I, I mean... I meant that there may be reasons why the organisation permits an unfeeling attitude to develop

V: Mmm.

R: as a protective mechanism but that, that was your suggestion because it would be exhausting to cope with suffering all the time.

V: Well I, I was taking that into account.

R: Yes, well it's uhh

V: Well I, I mean considering the number of years I've been going in and out of hospitals, I've only really realised since that dreadful experience in the National how much doctors do vary, not only in their ways of dealing with people but, you know, adequacy in their techniques in every way - and nurses. They vary as much as any group of people outside do. Maybe not quite as much but there ought to be a way, I know, I hate to say this but that Registrar who came to take the second lot of fluid out of my brain at the National. I saw him walking across the ward, not doing as I thought he should be doing on a crowded ward, to take the fluid out of my brain with no curtains drawn. I should have said something. I wanted to say something but even I, with all my experience and what you say, you know, I couldn't.

(At the National, when I saw the registrar who was coming to take the second lot of fluid out of my brain, walking across the ward towards me, not doing as I thought he should be, I was terrified and frozen. I had the strongest gut feeling that I should not submit to this - this man should not be a doctor and he didn't know what he was doing. Numerous contradictory rationalisations crowded through my mind as to why I should not stop him - on top of which was a fear it would be more dangerous to try. The status quo, the institution - the best hospital - would prevail. This self conscious, arrogant young man was coming towards across a ward crowded with visitors, with a piece of gauze already

soaked in dark brown fluid - drying rapidly - in one hand and a kidney bowl with syringe already set up with needle in the other. It was about 5.15pm, there were five visitors at the bed next to mine, three opposite and others elsewhere. He made no attempt to close the curtains round my bed and told me come and sit on the end of the bed next to him. I was aghast. I should have said something but I couldn't)

R: Why?

V: Because I wasn't sure that I was right and because I believed that my consultant who was supposed to be good would not let that man do it if he was not good enough.

R: So you had belief, an intrinsic belief in the system?

V: Yes, it was a young consultant. As far as I knew I was in the best neurology hospital in the country - if not Europe. This man surely would not be in his position if he were not pretty special. My consultant had spent about ten to fifteen minutes chatting to me, leaning against the wall near the desk, before lunch. During this chat he told me that this procedure was not a problem unless of course (he mimed) you pulled the fluid off the brain too quickly. In which case you might cause a thrombosis - a stroke - or similar. He departed with a friendly grin saying he would 'get one of his boys to do it.'

(I desperately hoped in advance that it would not be the one who came. (He had two registrars.) The man in question had personality problems that were openly discussed by the nurses, who said that he constantly told them he did not have enough confidence, this they did not believe since he behaved so arrogantly. He looked and dressed as though he might be a slick dealer in the 1980s stock exchange.

He had brought me the consent form for my operation on the night I arrived. He had not expected me to read it and was very impatient when I tried. It was impossible for me to read it with him fidgeting and I capitulated to the system since I knew there would be no alternative, but I asked him what would happen if the operation went wrong (neither my neurologist or surgeon had told me about the risks of brain surgery.) He simply grinned idiotically and said "We'll make it better". I gave up and he produced a fountain pen with red ink in it for me to sign - in the circumstances it looked like blood. He then tried to get an Indian - possibly Sikh - woman to sign and gave the same responses when she could not understand it. She was unhappy and refused until her husband came in later.

I have since decided that although my consultant was or is supposed to be very bright - the pathologist husband of the woman next to me had looked up his "form" - he was still in his thirties and he probably lacked experience both of casework and of leading his team. I know that registrars have to gain experience, but he was unaccompanied and I think in view of the state of my lungs the consultant should have taken particular care. Then I feel guilty for even thinking that.)

I've since formed the opinion that Ok, you know, he may be a brilliant technician and brilliant surgeon but he has not had enough experience of leading a team and he talked to me for twice as long in the morning, the consultant, as it took the guy to take the fluid out of my brain, he could have done it himself while he was talking to me. That sort of thing, you know, happens, you know. I suppose nobody's going to learn unless you're allowed to do things but....

R: But what stopped you? What, what actually stopped you?

V: I don't know, it was a complete nightmare because as soon as he'd done it and I'd realised he'd done it practically in a second or two and I thought, am I still sitting here because the consultant had told me in the morning that of course you can't draw fluids out of the brain quickly like that.

(I think I thought his personality was too unstable and I consciously spoke to him very calmly and quickly drew the curtains myself to shut out his audience, while he was telling me not to bother it would be over in a couple of minutes. I sat down on the edge of the bed dreading it. He took ages to find the right place along my scar, when he did he dabbed it cursorily, once, with the said piece of gauze without resoaking it and set about getting the needle in. When he was satisfied he pulled the fluid out very quickly - as quickly as I would think you could get fluid through a needle - and pulled it out and showed me it triumphantly. I was sitting in shock actually thinking "Am I still here?." It was bright (arterial) red fluid and frothed to fill the entire syringe. He said "there you are - 10mls." And I thought it was considerably more. I said, still calmly "I thought brain fluid was a sort of grey colour and he agreed it was but said there was a lot of blood in this. I wanted someone else to see it but I couldn't move.)

R: Yes.

V: The consultant said, you know, do it slowly. I had a long conversation with him and then suddenly this man comes in and does that.

R: Why did you allow it to happen?

V: Are you saying it's my fault now?

R: No, no, no, not at all. Can I clarify that? I don't think it's your fault.

V: No, it's a joke. I know what you're trying to say but I can only say that most patients, without my, my experience would have been even less likely than I would to have objected.

(Reasons: There was my belief in the system, considerably reinforced by the fact that I was in the specialist hospital in the field. Also my choices about the management of my illness over the last twenty years has meant that I have not been in hospital much in that

time, most of my experience of hospitals until then was earlier in more rigorous times. I personally think that procedure should not have been done outside a treatment room with a nurse present, but knew nothing about neurology and it all seemed outside what I knew about.

It seemed to me that the problems associated with the cyst in my brain were in all senses completely outside my control. It is important to me to feel that I have some control over my illness so that I can act in ways that will not make it worse, and if not healing will at least make me feel better or more comfortable. With the brain there was nothing I could do. I had tried to exercise my weak legs to make them stronger, but all it did was totally exhaust me. The messages from the brain were not getting through. I think this long and steadily worsening experience had already created a sense of powerlessness.

All this was reinforced by the way the ward in the National was run. It took only immediate pre-op and very ill post-op patients who were mostly too ill to talk to each other. The nurses when not performing necessary tasks were always at their station, talking to each other or the younger doctors. There is the (story of the paralysed, blind woman opposite me who I found out did not know why she was there because no-one had told her. She, with all her limbs strapped down, wearing dark glasses and stuck two feet in front of the television all day, with a perfectly active mind and voice ignored, epitomised to me the unpredictability and sense of being wholly out of control of oneself experienced by neurological patients.

When I had the major seizure about 3 hours after the withdrawal of that fluid there was even in those split seconds as it happened a dreadful inevitability about it. The pain was of an order which I had not thought possible - it was inhuman. Electrical current not related to ones shape or previous sensations enough to fell a huge old tree. The next day it was all played down and my anger was too deep and confused to be expressed.)

R: Well what I'm suggesting....

V: But how could I have got round it? You tell me. Apart from just objecting then and making a fuss. You see, every patient thinks if they make a fuss then all the staff are going to lay into them from then on because they don't like people who make a fuss.

R: Yes.

V: The nurses don't like it, the doctors don't like it. In actual fact it's possibly the reverse. If somebody does come in and demands to be treated properly in hospital nowadays, they usually make sure they are because they know this person's going to make a fuss if they don't, but that's very rare. Nobody knows that and I, I didn't even feel, I mean, knowing it and feeling it is two quite different things. I didn't even think that until later. I've been over that moment so many times and I'm not over it now – after nearly two years it is still a emotional drain on me and although I have wanted to write and complain I have been unable to do so. I also think that the surgeon should not have

allowed him to do it in my case. I think, why should I think that arrogantly but I think that with lungs as bad as mine, that they should have taken extra care. Umm I wasn't even told beforehand that you know, there was a possibility of strokes or epilepsy with brain operations anyway.

R: So Val, you seem to suggest that not only was there the hospital, but behind that there was, there was a kind of surgical institution that's giving authority for them to do things to you.

(sorry did not really answer you here but there is another point)

(I don't know whether I can take that any further but I would say yes, and the thing that made it worse was the degree of blinkered specialisation that was going on, not only did they not take regard of my situation with very bad lungs, but they could not even write up my respiratory drugs properly the whole time I was there, in spite of several times asking for them to be corrected. This in itself caused me some degree of discomfort, before starting on my brain.)

V: Oh yes, that's the trouble, the arrogance but on the other hand you see, I don't believe that in breaking down a, a hierarchy in a visual sense, say by uniforms

R: Yes.

V: or some other basic way is going to help. I think it has, you have to maintain a structure where there is a clear line of authority and there's a clear means of working.

R: Right.

V: and I, I think you have to absolutely have that. If you haven't got that the patients will feel more insecure and I think terribly so. I don't like not even knowing who the staff nurse is, I don't like not knowing who the sister is on the ward. Basically if you're a patient, you'll probably never do it, you'll probably never talk to them but the feeling that somebody there is actually, you know, responsible

R: Yes.

V: for what's going on helps you, it's a helpful feeling.

R: Yes.

V: It's still quite frequent that you'll get a sister who never talks to the patients at all now.

R: So the structures are, you're saying are both, both helpful and inhibitory in some ways so

V: No they're not inhibitory on the patients sides. I mean, the structure itself and the line of, line of authority is good. What, what's built up behind them is a kind of an assumed position within institutions

R: Right.

V: Which I don't think is necessarily that conscious anymore in people but it, it, it's habits, die-hard and the habits can be ways of thinking not just doing things.

R: Mmm.

V: and umm I just think that if, I know that there's a cut off point where doctors, as I've said just now, need to protect themselves from breaking down in, you know, emotionally for what they see all the time but they still have in some respects to look at every patient as a person

R: Right.

V: and you actually find quite often that the consultants are better at doing that than the younger doctors because younger doctors are more terrified, they're more worried about the consultant than the patient. Now they're much more worried about doing the right thing you know.

R: The Consultant? Sadly we're having to watch the time a bit. Val can I, would it be Ok to sort of wind up a little. Is umm, I have a sense I've slightly pushed you on certain points. Has that been Ok?

V: Well I haven't minded. I have a sense I haven't talked about what you want.

R: Why?

V: You know, I didn't know what you wanted, I just covered, done my own thing a bit.

R: Well umm I, I think you've said some really fascinating things.

V: I think there's a very big deal within the medical profession about patients being at all involved in umm either the way of running things or taking decisions about anything within hospitals I mean from their own actual treatment to you know

R: To the way hospitals are run and all the rest, yes.... Can I clarify one thing? You have no fear that what you said has not been interesting, it's been fascinating but I, I, I also have a slight anxiety that there have been moments where I've pushed a little bit to kind of

explore in a bit more depth what you've meant about certain things but also to check out some of my own interpretations. Is that right?

V: Yes

R: You felt it appropriate. Ok. Right. Is there anything you wanted to add?

V: No, I mean on my own, I actually want , you know me, I'll probably never get round to it because while I'm working, I'll never have the energy

R: Yes.

V: I'd love to write something...

R: About your experiences.

V: I'd love to do something about my experiences, the experiences of chronic illness patients.

R: Right.

V: particularly in hospitals and I'd love to do something about the use of steroids which I have to say, I didn't quite finished because I, I think they're still used far too much and asthma is getting more and more common in children and I know that there, everybody is saying that inhaled steroids are not as harmful as swallowed steroids which is, which is undoubtedly true. But the really long term effects of being on inhaled steroids are not known yet, and doctors and I thoroughly, this is where nursing comes in again, I really feel that doctors feel there is nothing they can do for respiratory patients and I don't know whether it's the same in other areas with steroids use . The doctors are very frustrated when there's nothing they can do for people and I sympathise completely

R: Yes.

V: and umm they feel they've got to do something and steroids are a way of slightly minimising etc etc but last time I was in hospital, there was a girl, 25, had brittle asthma and she'd been put on steroids had asthma again, this always happens, asthma again, the doses got higher, asthma again, the doses got higher, she was on 80mg a day and they had to get her off it. Once they'd got it right, they couldn't get her off it. She'd have asthma again. What do they do when she has another huge attack you know, it, it's, it's not the answer. Steroids are not the answer I believe and I think they've grown in popularity because doctors feel impotent in not being able to handle certain problems in any other way.

R: Right.

V: I think nursing is part of it and I think, I know that sounds crazy, but I think with asthma it's a terribly scary thing to get, especially probably for children but I didn't actually panic about asthma until I was in my 20's and I felt quite safe until then oddly enough but when it's a scary thing, if everything around you seems out of control umm it's terribly important that it's brought back into control and you feel as though there's somebody, or people around you who are caring and are not going to miss anything and you get you know, you feel safe. I actually think that really good nursing can play a part in

R: mmm

V: in the asthma treatment, by that I mean perhaps more than ever been done even unconsciously in the past.

R: Val, I, I'm sorry,

V: That's it.

R: No, no it's not that. We're just starting to run into a problem of time really. I have to pick up my little boy from school.

V: I thought you were....

R: Can I just check the - yep it's all gone. Absolutely fine.

THE END